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ABSTRACT

This paper examines the role that public policy and practice play in supporting the efforts of natural, adoptive, and foster families who have children and youth with disabilities in keeping their families intact. Obstacles and barriers to implementing the philosophy of permanence planning, especially for children and youth with disabilities, are discussed. The paper: (1) describes programs sponsored by various state and private agencies that have overcome these barriers; (2) reviews Illinois expenditures in family support, showing that there is a need to increase fiscal and program effort; (3) discusses services for children and youth who are removed or placed out of their natural homes, but for whom adoption, foster care, or other alternatives to institutional care have not been made available; (4) contends that the state's extensive use of out-of-home placements not only works against the goals of permanence planning, but diminishes the state's ability to fund supports and services that would enhance the ability of families to keep children at home; (5) outlines concerns related to the risk of child abuse in out-of-home placements versus the risk of abuse in family homes; and (6) offers excerpts from state reports on government-funded residential facilities that provide residential services and active treatment for persons under 22 years of age. Fifteen recommendations for Illinois policy development are presented. Appendices contain an annotated bibliography, a list of licensed children's facilities, and descriptions of deficiencies cited in surveys of state facilities. (Contains 48 references.) (JDD)

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ILLINOIS – IT'S 1993, DO WE KNOW WHERE OUR CHILDREN ARE?

An Examination of Trends and Practices in In-Home Family Supports & Out-of-Home Placements for Children and Youth with Disabilities

STATE OF ILLINOIS

Prepared by
The Illinois Planning Council on Developmental Disabilities

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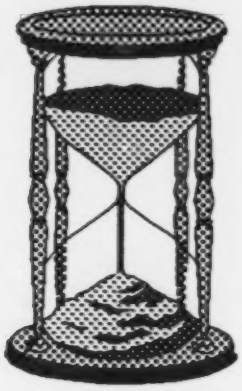

Illinois -- It's 1993, Do We Know Where OUR Children Are?

An Examination of Trends and Practices in In-Home Family Supports and Out-of-Home Placements for Children and Youth with Disabilities

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Introduction: A Call to Action

Illinois -- It's 1993 is an issue paper that was prepared by the Planning Council during the summer of 1992, pursuant to a request by the Illinois Department of Children and Family Services (IDCFS) for information related to best practices and trends in foster care and out-of-home placements for children and youth with disabilities. The paper was updated in February, 1993 with additional data coming from DCFS and DMHDD on out-of-home placements and their costs.

The trends reviewed in this paper show that the United States has decreased reliance on institutional care for children and youth with disabilities in favor of family-centered services and supports. **The primary focus of the paper is on the important role public policy and practice play in supporting the efforts of natural, adoptive and foster families who have children and youth with disabilities in keeping their families intact. The philosophy the U.S. Congress intended for states to use for all families and children in need of government intervention is called *"permanence planning,"* which involves targeting this intervention at providing all children and youth with a supportive and consistent family.** As documented in the paper, however, there are many obstacles and barriers to implementing the philosophy of permanence planning throughout the nation and in Illinois, especially for children and youth with disabilities.

The paper describes programs that have overcome these barriers, successfully translating philosophy into practice. These programs are sponsored by various state and private agencies around the nation. They could serve as models for the state of Illinois in improving its family support, adoption and foster care programs for children and youth with disabilities. Moreover, these programs are vitally important in promoting the goals of permanence planning. Therefore, in addition to the findings and recommendations for IDCFS that emerged from the Planning Council's research into trends and best practices, the paper reviewed recent expenditures by the Illinois Department of Mental Health and Developmental Disabilities in family support. This review shows there is a dire need to increase the fiscal and program effort by the state of Illinois in family support.

The paper also discusses services for children and youth who are removed or placed out of their natural homes, but for whom adoption, foster care or other alternatives to institutional care have not been made available. National trends in out-of-home care of children and youth point towards a dramatic downsizing out-of-home residential facilities. By contrast, large facilities still dominate residential services provided in Illinois for children and youth with disabilities. The state's extensive use of out-of-home (and out of state) placements not only works against the goals of permanence planning, but diminishes the state's ability to fund supports and services that would enhance the ability of families to keep children at home, as well, due to the ever-increasing cost of providing long term institutional care of children and youth. National and state level concerns related to the risk of child abuse in out-of-home placements vs. the risk of abuse in family homes are also presented in the paper.

Illinois -- It's 1993 ends with excerpts from recent Illinois Department of Public Health survey reports on residential facilities funded by the federal and state governments to provide residential services and active treatment for persons under 22 years of age. These excerpts bring the paper's focus to it's sharpest resolution: **these reports are written about real children and youth, who, through no fault of their own, actually are growing up in an institution, instead of at home with a family.**

The Illinois Planning Council on Developmental Disabilities is calling for all Illinois policy makers to take action to develop alternatives to institutional care for these children and youth. Every child should have an equal opportunity to grow up with the support and care of a loving family. The clock is ticking for Illinois children and youth who need family care and a responsive service system. The State must take immediate action on their behalf.

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Recommendations

1. The state of Illinois should base all efforts made to reform services for children and supports to their families on the philosophy of **permanence planning**. All children, no matter how severe their disabilities, deserve an opportunity to grow up in a family home. State agencies serving children and youth with developmental disabilities should conduct research into existing legislation, rules, regulations, policies and practices to **identify and remove barriers to permanence planning**.

2. The Illinois Department of Children and Family Services should work in conjunction with other agencies to **translate the philosophy of permanence planning for all children into effective state policy**. Translating this philosophy into practice recognizes not only the rights of the children and families involved, but also the economic benefits to the state of avoiding the costly institutionalization of children.

3. As a part of an overall strategy to decrease Illinois' reliance on ICFs-MR, the state of Illinois should consider both **a moratorium on further ICF-MR development** and implementation of a five year plan to **downsize ICFs-MR for children and youth**. Services for children and youth currently served in those facilities could be funded with the federal Medicaid Home and Community Based Waiver Program. The goal of these services and supports should be to give these children and youth an opportunity to grow up in a family home. This may include returning children from facilities to their natural families or it may entail developing adoptive or foster family homes for them.

4. **Planning, coordinating and implementing family support and out-of-home services for children and youth should be done on a local community level, with state support, using a variety of funding sources.** The Medicaid Home and Community Based Waiver dollars that would become available, as described in the preceding recommendation, with the downsizing of ICFs-MR for persons under 22 years of age would provide impetus for this approach. Waiver funding made available as children and youth leave institutional settings could be used to enhance or develop independent case coordination and community supports. In addition, local service and support networks, composed of parents of children with disabilities, public and child welfare agencies, health and mental health agencies, educators and case coordinators, could be organized, by the independent case coordination agencies, to develop and implement local community plans for meeting community needs for family support and out-of-home services for children and youth. Developing service networks or enhancing existing networks would not add another layer of bureaucracy through which families and service providers would need to negotiate. In each local service network system, single, independent case coordination agencies would be made solely responsible for arranging services and supports based on family or individual service plans. This streamlined, systems approach is a stark contrast to the current, uncoordinated, duplicative, non-system for planning, coordinating and implementing community-based supports and services. Creation of these networks would also assist existing agencies in functioning

more efficiently and cooperatively, through local planning and service implementation that would clarify roles of local and state agencies within the local service system and, consequently, would decrease service/support overlap and duplication. These service and support networks would be accessed by families through a **single point of entry (i.e., independent case coordination agencies)**, to provide:

a. **case coordination (service facilitation) that is independent of service provision.** The best way to provide independent case coordination (service facilitation) that integrates the services and supports funded by a variety of state agencies would be to **merge existing case management systems under an entity that is independent of funding sources and service providers**, so that duplication, bureaucratic obstacles, and turf issues would be eliminated and so that families would have a less difficult time accessing state-funded services and supports. Until the merger of these systems occurs, service network formation would assist local and state agencies (DCFS, DSCC, DORS, DMHDD, and DOA) in developing closer working relationships to benefit families.

b. **a menu of individualized services and family supports**, that focuses on family preservation, including developing or accessing natural community supports for families, funded, facilitated by, or provided by local and state agencies, from which families could choose desired services and supports.

c. highly visible local community efforts to **promote the adoption of children and youth with severe disabilities.**

d. equally visible local community efforts to **recruit foster parents for children and youth** who are waiting for adoption or who are currently placed in congregate care that would be supported by an extra state subsidy for respite for foster parents and state regulations that would ensure that foster and adoptive families qualify for <u>all</u> state-funded family supports (also, see recommendation # 9).

e. flexible methods of **channeling direct payments for services and supports to or through natural, adoptive or foster families** to meet their needs, through the use of cash stipends, vouchers, or "quick"/"easy" (credit-style) cards.

5. The **role of Illinois state agencies** in developing local service networks **would be to fund organizational support of the networks through the local case coordination system and to function in an advisory and technical assistance capacity.** This training and technical assistance role for state agencies would be similar to the role of state agencies envisioned by DSCC's FOCUS project. The **role of families of children and youth within these local networks would need to be strengthened.** Case coordination agencies in local areas should engage in empowerment activities, such as those represented by self-advocacy support, partners-in-policymaking, and "parents as case

manager" training programs, to enable parents to function effectively in these networks. Formal and informal organizations developed to advance service network formation (consisting of public and child welfare agencies, health and mental health agencies, educators and service providers, organized by case coordinators) should include parents of children with disabilities, pursuant to P.A. 87-977.

6. **Local service networks would need to address the needs of culturally diverse communities** whose members include African Americans, Latino Americans, Native Americans and Asian Americans and/or other ethnic groups. Additional preservice and inservice training should be provided on an ongoing basis to all local and state agency staff who work with members of communities that are culturally diverse, to make them sensitive to different points of view with respect to family composition, the use of language within those communities, and cultural mores.

7. The Illinois Department of Children and Family Services should aggressively pursue federal funding to **complete its implementation of the Foster Care Initiative** and to **improve adoption practices**. Also, the Foster Care Initiative should be updated, as the advocacy work led to its creation took place seven years ago, and the structure of DCFS as well as the needs of foster parents are likely to be different now. Possible methods for increasing funding for these activities would include capturing federal grants such as those offered by the Department of Health and Human Services' Adoption Opportunities grant program as well as other federal and private grants. In the future, **communication must be improved between agencies** whose primary mission involves serving persons with disabilities (Illinois Department of Mental Health and Developmental Disabilities, Illinois Department of Rehabilitation Services and the Illinois Planning Council on Developmental Disabilities) and the Illinois Department of Children and Family Services. These agencies need to engage in an ongoing strategic planning process for cooperation, coordination and collaboration across these state agencies to develop a common vision and goals as well as to commit specific agencies to specific actions each will take to implement these goals. This process might involve one agency assisting another in grant submission, such as the Planning Council working with IDCFS to obtain grants to support its Foster Care Initiative. This process would ensure that every opportunity to capture federal and private foundation funds is taken.

8. If the Illinois Department of Mental Health and Developmental Disabilities demonstrates its ability and commitment to expend all funds allocated for the purpose of family support, **additional family support funding should be sought to fully fund this program for all eligible families**. Additionally, the Department should seek approval of family support as an option under the federal Home and Community Based Waiver program, to decrease reliance upon general revenue funds as the only source of funding for family support.

9. The Illinois Departments of Mental Health and Developmental Disabilities and Children and Family Services should work together to **ensure that families who adopt children**

with severe disabilities and foster families that include children with severe disabilities in their homes are eligible for the full range of family supports available to natural families, in addition to whatever other incentives (medical stipends, foster care payments) are provided to them.

10. The Illinois Department of Children and Family Services should immediately implement a program for **in-service and preservice training of and technical assistance to DCFS case workers, adoption staff, and resource development staff on current best practices**, with advice and support from people with disabilities and families having children with disabilities, advocacy organizations, DMHDD, DORS and the Planning Council in: recognizing developmental disabilities; functional assessment techniques; and service facilitation and futures planning. A train-the-trainer model could be used that would bring in nationally-recognized experts in family support, adoption, and foster care. This training effort should define the outcomes it would be intended to produce, in advance, and these outcomes should be evaluated at appropriate intervals after training, setting 1996 as the target date for achieving all outcomes. The primary objectives of this training and technical assistance should be to:

    - ensure that caseworkers screen and accurately identify and refer for appropriate assessments all children and youth who appear to have a developmental or other disability and who would require supports and services to preserve families and meet the needs of the children and youth;

    - arrange functional assessments for the children who are identified in the screening process as possibly having disabilities;

    - ensure that caseworkers make referrals to existing independent case coordination agencies wherever these services are available (using these as "single points of entry" as they are developed), to arrange for individualized family supports the family requests or for appropriate out-of-home services (as when children are removed from their family homes due to neglect or abuse);

    - increase the number of Illinois children with disabilities living with their own families, or with adoptive families and permanent foster home placements when natural families cannot be preserved; and

    - increase family satisfaction with supports and services.

11. The Illinois Department of Children and Family Services and other state agencies should **routinely produce data about outcomes for families, children, and youth -- at a minimum, this data should identify the number of children with developmental disabilities in all DCFS programs.** These data should be regularly exchanged with other state agencies to improve interagency strategic planning.

12. The Illinois Department of Mental Health and Developmental Disabilities should take the lead in an interagency effort, that would include IDMHDD, the Illinois State Board of Education, the Illinois Department of Children and Family Services, the Planning Council and the Community and Residential Services Authority to **reexamine the number of children and youth currently in out-of-state placements.** These placements are very costly and work against the goals of permanence planning, making it very difficult for natural families to maintain ongoing relationships with their children. The Department should **develop a plan to determine what kinds of services and supports need to be put in place to return the children and youth of Illinois to their home state.** The Department should also establish a policy that would **prohibit additional out-of-state placements for children,** in favor of expanding in-home family supports and brief, local, out-of-home residential and treatment services, to be used, when necessary and appropriate, for short-term medical or behavioral treatment. Local communities must share responsibility with state agencies for planning, implementing and monitoring services and supports for families, children and youth whose intensive needs have, in the past, led state agencies to accept sole responsibility for meeting these needs.

13. **Legislation should be passed, or an interagency agreement should be reached, to mandate administration of a single set of standards for out-of-home residential services for children with disabilities.** Existing legislation (P.A. 87-996) would suggest that the Illinois Department of Mental Health and Developmental Disabilities would have the authority to develop such an agreement for Medicaid-funded services, but IDMHDD may lack the authority to administer funds for children's residential services that originate from federal child welfare grants. Therefore, additional legislation may be necessary. The agency chosen to administer a single set of outcome-oriented standards should be the same one selected for this purpose under the agreements called for in 87-996. In addition, systems for quality assurance and community monitoring should apply to children's as well as adult services. **Quality assurance and community monitoring should focus on permanency planning outcomes for children and youth**: e.g., do facilities actually place children and youth with disabilities in adoptive or foster families or are children and youth long-term facility residents? Do children and youth with disabilities remain free from abuse?, etc. The outcome-oriented standards developed by the Accreditation Council under a grant cofunded by the Planning Council and the Illinois Department of Mental Health and Developmental Disabilities, as well as other outcome-oriented standard development could be used by the designated agency as examples of how standards could be focused on outcomes for children and youth.

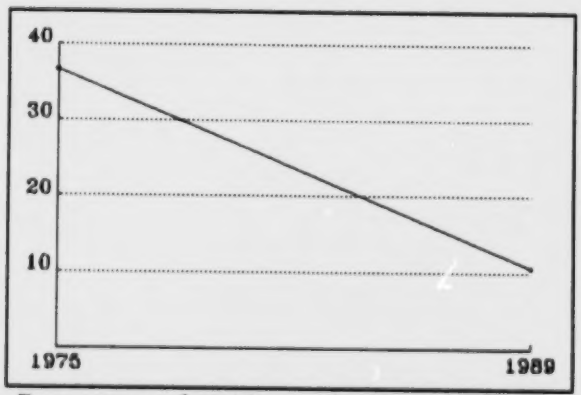
14. The state of Illinois should examine what proactive steps the state now engages in to prevent abuse of children and youth in out-of-home residential services. The state of Illinois should **adopt universal abuse prevention and intervention policies and procedures that apply to all out-of-home placements for children and youth.**

15. The state of Illinois should **give incentives to agencies that currently provide out-of-home residential services to children with disabilities to move quickly to return these**

children to safe and caring families and begin to provide a range of permanency planning services and supports to families, children and youth. Some of the permanency planning service options agencies should be encouraged to explore include: providing respite services, service facilitation, short-term residential behavioral or medical treatment and supervised foster care.

Trends Away From Large Congregate Care

There is a "historical trend away from an emphasis on large congregate care to an increasing emphasis on community and family care . . . (this) trend toward deinstitutionalization involved both avoiding initial placements of individuals in state institutions and discharging residents of these institutions into the community." (Heller, et.al., 1992, pg.2) By 1988, the total number of people with developmental disabilities in all of the nation's public institutions had dropped to about 91,000 (Braddock, et.al., 1989), down from the highest population, of 194,650 in 1967 (Rotegard, et.al., 1984), a 52% reduction in 22 years. Lakin (1992) reports the number of persons living in all state-operated Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) as of June 30, 1990 was 81,629. The number of persons living in state-operated facilities housing sixteen or more persons dropped 29,815 since June 30, 1982, a 27% reduction in population in only eight years. Many state operated institutions for people with mental retardation have been closed altogether; with the decision to close two of its thirteen state institutions, Texas became the twenty-forth state to close or recommend closure of large institutions. Between 1970 and 1992, 44 institutions were closed in 22 states and another 27 are recommended for closure (Texas Planning Council, 1992).



Percentage of residents of public institutions in the U.S. who were children with developmental disabilities, 1975-1989

This trend away from large congregate care is also evident in the declining number of children in institutions in the United States, reported by Scheerenberger (1988, 1990), and illustrated in the figure to the left. In fact, the average overall size of private child welfare institutions nationwide has been cut in half between 1966 and 1981 (Young, Dore, & Pappenfort, 1989). There also have been changes, not only in the numbers of people living in public institutions, but in the attempts by these facilities to provide more home-like environments by creating smaller living units within institutions. With these trends in decreasing populations, size and numbers of public institutions, there have been increases in the use of private institutions for out-of-home care of children and youth with severe disabilities and in the use of family support programs to keep children and youth at home, with their families. Even with increases in the use of private institutions, *it is much more likely today, than it was even twenty years ago, for children and youth in the United States with severe disabilities to live in a family home* -- with their own families, with adopted families or with foster families, than it is for them to live in a public or private institution. National studies have found that about 90 percent of children and youth with developmental disabilities live at home

with their families (Agosta, et.al., 1991).

In spite of the dual trends toward family care of children and youth with developmental disabilities and community-based provision of services for children and youth requiring out-of-home care, **most states spend a disproportionate amount of money on institutional out-of-home care vs. what they spend on supporting family caregiving and community-based service provision.**

Family Support

A key factor in the trend toward greater numbers of families keeping children with severe disabilities at home, according to Nisbet, Clark and Covert (1991), has been the availability of family supports. They observed that most states offering family supports and services began funding family support programs within the last twelve years, as the costs of institutional care began to skyrocket and families began demanding alternatives to institutionalizing their children. A variety of supports and services have been designed that can help families keep children with severe disabilities at home. These supports and services are designed to assist the whole family, not just the person with a disability. Current best practices nationwide suggest that the philosophy that should guide states in implementing family support programs is that **policymakers should do "*whatever it takes*" to keep the family intact; to maintain and enhance the family's ability to care for children and youth with disabilities at home; and to prevent costly and disruptive out-of-home placements** (Knoll, et.al., 1990; Taylor, et.al., 1991; Agosta, et.al., 1991). This may include: granting cash subsidies, offering or reimbursing parents for in-home or out-of-home child care, modifying the home to make it more accessible, providing adaptive equipment, counseling parents, intervening in crisis situations, offering in-home or out-of-home respite care, paying for supplemental medical or dental care, assisting families in accessing or building natural support systems, providing in-home nursing and attendant care, educating parents, facilitating recreation, and making vehicle modifications.

Unfortunately, as Knoll, et.al. (1990) state, "compartmentalization of family support and the lack of interagency collaboration" exist throughout the nation. Children and youth with developmental disabilities are eligible for some form of assistance from some or all of the following agencies in each state: health, Maternal and Child Health, Title V, social service, mental health, retardation, child protection, education, early intervention, pilot projects funded by developmental disability councils and others. "This leads to a situation in which a family may be eligible for a program but never hears about it because the primary contact is with providers who are involved with another state department and know nothing of benefits available outside that funding stream." (pg. 11) This emphasizes the importance of including what traditionally has been labelled "case management" services (referred to now by other labels, such as "service coordination" or "service facilitation") in family support programs. **Service facilitation makes parents aware of what government assistance or natural support systems are available and helps them obtain needed services and supports.**

Providing support and service coordination to families is not a new idea. In 1977, at the first

National Conference on Institutional Maltreatment of Children, a seminar group working under the topic heading, "mental retardation in the institution," recommended:

- closing institutions;
- providing family support systems in the natural home;
- removing children from the home only after appropriate services have been provided and failed and either a child is threatened with irreparable harm or the child's life is threatened;
- providing foster care as the first alternative if a child is removed from the home; and
- initiating legislation or reforming policy and practices that would enhance both the rights of children and advocacy and protection for children.

In the "mental retardation" seminar at the 1977 conference, recommendations included making subsidies available to families to help them pay the extra costs of caring for a child with a disability and the creation of early intervention programs, respite care, homemaker services, visiting nurses, personal assistance and parent education.

Model Family Support Programs

Nisbet, Clark and Covert (1991) describe several model family support programs they believe represent current best practices. The two programs, below, provide very flexible, user-friendly features found to be essential to the success of family support.

- **The Michigan Family Subsidy Act** This act provides eligible families with $225 a month to be used at the parents' discretion. Eligibility is limited to families with incomes below $60,000 a year who have a child under the age of 18 with severe mental impairments living at home. In 1990, there were 2,500 families enrolled in the program at a cost of $6.7 million. An evaluation of the program published in 1986 (Meyers & Marcenco) showed that participating families experienced a significant reduction in stress and that there was a decrease in plans to seek out-of-home placement. Heller, et.al. (1992), note that Michigan is the only state that spends more than one percent of its total developmental disabilities service budget on cash subsidies for eligible families.
- **The Wisconsin Family Support Program** The primary feature of this program is service facilitation -- helping families to prepare a comprehensive family plan and then to obtain services and supports from government funding agencies, as well as helping families use generic community resources. Up to $3,000 in vouchers can be allocated per family per year to fund any needed equipment or

service documented in the family plan. The program is administered by individual counties.

Both of these programs are based on the principle that **family supports should maximize the family's control over the services and supports they receive** (Taylor, et.al., 1991, pg. 17). By giving the family control over how they spend cash or vouchers, the Michigan and Wisconsin programs have recognized that families are in the best position to decide what they need and what is important to them. A study of pilot family support programs funded by the Illinois Planning Council on Developmental Disabilities showed that of families receiving cash assistance, 98 percent of the families surveyed said they had "enough" or "more than enough" control over spending the money (Agosta, et.al., 1991). When asked how much the family support program had influenced their decision to have their family member continue living at home, 38 percent said it had been a moderate to a great influence. In another study of a Family Assistance Program in Illinois, that offered cash stipends to a limited number of families in the state, Goerge, Osuch, Costello and Casey (1992) found that, overall, parents receiving cash stipends were very satisfied with it, with 73 percent indicating that it had eased their financial worries and 79 percent feeling that the stipend had improved their ability to care for their child with a disability.

The state of New York piloted a family reimbursement program, designed to afford families a great deal of flexibility, in which families obtained and paid for whatever services or goods they needed and then obtained reimbursement from a not-for-profit intermediary agency for the cost. These intermediary agencies would also pay directly for the service or product when the family was unable to pay in advance. In an evaluation of the New York program, Schwartz and Giblin (1991) found that 95 percent of responding families indicated the reimbursement services helped them and 99 percent rated them as either "good" or "excellent." Families participating in the evaluation commented that they **liked the fact that they had a *choice* in selecting service providers** (many families recruited, trained and hired their own respite care workers from their immediate neighborhoods) and **felt they had a sense of *ownership* in the program**, since they had input into and control over what the program provided.

Community and Home-based vs. Institutional Treatment

Research on *treatment effectiveness* also supports the philosophy of working with children with disabilities in their homes, rather than placing them in residential programs. A study of the relative effectiveness of behavior intervention in three different settings for children with autism was conducted by Sherman and Barker (1988). Only the *home-based* group showed significant improvements on the behavior observation measure. In their discussion, the authors state,

> it makes more economic sense and clinical sense to attempt nonresidential forms of interventions with . . . children (with autism), since it is cheaper and less intrusive. In fact, up to three times as many children can be treated in an outpatient setting, compared to the number treated residentially, with the same resources . . . By involving the parents and sometimes the rest of the family, generalization becomes built in at home. Parents

> can act as tutors and behavior therapists for their children . . . Our experience is that there are certain times and certain children where residential treatment *is* indicated . . . Short-term residential treatment may be indicated when a child who is being treated on an outpatient basis becomes unmanageable: there may be a need for residential intervention to accurately assess the problem and get the behaviors under contiguous control . . . (in addition) some children may be extremely aggressive and may require residential treatment or long-term residential placements . . . However, long-term residential treatment should be used with caution. Residential treatment, if carried out for a long period of time, has several deleterious side effects: parents lose the motivation and desire to have their child at home; the parents' ability to manage their . . . child decreases the longer the child is away; parent-child bonding loosens and the parents become less important figures in the child's life . . . (pgs. 119-120)

Children with needs similar to those of children with autism are expected to benefit from the passage of Senate Bill 1306, which authorizes a program of federal block grants to the states (National Mental Health Association, 1992). Under this legislation, the federal government will develop a new Center for Mental Health Services, to administer all federal mental health services programs, including a new children's program. The funds provided under this program are intended to enable states and communities to **develop *local* systems of care**, consisting of mental health, child welfare, education and other appropriate agencies for children having serious emotional, behavioral or mental disorders. Funds would be authorized for services that are currently underdeveloped or nonexistent in most communities: diagnostic and evaluation services; outpatient services in clinics, schools, or other appropriate settings; emergency services; intensive home-based services when the child is at imminent risk of out-of-home placement; day treatment; respite care; therapeutic foster care; therapeutic residential or group homes for not more than 10 children; and transition to adult services.

Needs of Children "At Risk" of Institutionalization

In their study of health care financing for children with intensive behavioral and medical needs, Birenbaum, Guyot and Cohen (1990) found that families had substantial problems obtaining health care (including the above-mentioned mental health and support services). The authors found that the families in the study who had children with autism paid an average of $900 in out-of-pocket medical expenses annually, whereas the average out-of-pocket annual spending for parents of children with severe and multiple disabilities was $1,600. **Some of the families spent more than 20% of their income for medical services.** The authors state that "proposals to increase assistance to families (having) . . . children (with severe and profound mental retardation) must seriously consider a targeted approach to those with extreme medical needs. The burdens are many for the few families who must care for children who require enormous amounts of health care as well as educational resources." (pg.104) The authors recommend that "the health care requirements of these children should be viewed broadly so as to include personal care and family support necessary because of their disabilities." (pg. 115) Furthermore, they recommend that "financing should promote family-centered care." (pg. 115)

In addition to suggesting many private and public sector strategies for reforming the health care system to better meet the needs of families having children with disabilities, one of the strategies for meeting family needs suggested by the authors was to expand case management through the federally-financed Children with Special Health Care Needs program. This recommendation was made based on their finding that a "substantial majority" of families that had case management services judged the medical services obtained through case management to have improved their children's lives. They cite model Children with Special Health Care Needs case management programs in Florida, Iowa, Michigan and Los Angeles.

Parents as Case Managers

Besides the approach of providing service facilitation to families through agencies such as those funded by the CSHCN system or mental health and developmental disabilities agencies, alternative approaches to case management include **teaching parents to become their child's service facilitator**. The Parent Case Management Program at the University of Minnesota provides "tools to assist persons with disabilities and their families to take active roles in determining the services and resources they need and the way those services and resources are delivered." (McBride, 1992A, pg. 8). Participants in this training program show improved abilities to assess their children's strengths, progress and specific needs; increases in knowledge of service rules and regulations; more effective relationships with other interdisciplinary team members; and better linkage with community resources and social networks.

The Minnesota program was based on the work done by Matt Pope (McBride, 1992B) and others in California. Pope responded to an information request by the Illinois Planning Council on parent training programs in California with a letter describing Parent Program Coordination, which the Eastern Los Angeles Regional Center for the Developmentally Disabled, Inc. has established as its main form of case management. The Center starts

> with the assumption that parents inherently want to be program coordinators and that they are competent to do so. At all times the parent is given support and training and the family member who is disabled will not suffer from the implementation of this model . . . the issue is attitude. Instead of thinking parents don't want to be troubled, are too busy or not competent, we expect parents to be interested in being literate in understanding the service system and willing to act on behalf of their family member with a disability. (Pope, 1992)

The philosophy and purpose statement of the Parent Program Coordinator Training program, describes the 14 year-old training model as a "hybrid of professional practices and forms of parent training and support. The recently revised model focuses more on adult education through which parents can learn to work effectively both with their children and with professionals." (State of California, 1992) Copies of the training curriculum may be obtained from the principal author of this paper at the Planning Council.

Out-of-home Placements: Reasons, Philosophies and Types

Children are placed out of their natural homes on a voluntary basis usually due to the inability of the parents to cope with the demands of caring for a child with severe disabilities or when the service system does not provide families with the resources needed to maintain children at home. This is particularly true when behavioral problems or severe health problems exist. Children with severe disabilities are removed from parental custody on an involuntary basis when child protection agencies determine that severe neglect or abuse has taken place. Most often, children who must leave their natural homes are placed in another family home with one or two consistent caregivers, such as in foster care; or they are placed in facilities that are staffed by shift workers, such as pediatric nursing homes, intermediate care facilities for the mentally retarded (ICFs-MR), or group homes. As stated earlier, the number of persons with developmental disabilities has increased, nationwide, in both small and large private facilities (ICFs-MR with capacity for more than 15 people) and nursing homes, a trend that is contrary to the philosophy of *permanence planning* (Cole, 1989).

The primary goal of permanency planning is to secure for all children a caring, legally recognized family in which to grow up. This goal applies equally to children who are at risk of being removed from their natural families and to those who have been placed out of or removed from their natural families. When it is not possible to arrange for an adoptive family in which to grow up, permanency planning seeks to reinforce ties to nurturant foster parents or caretakers. Permanency planning is the stated philosophy in both national legislation and the administration of federal child welfare agencies. This philosophy emerged after the success of the Oregon Project, a federally funded project at Portland State University in Oregon in the 1970s (Maluccio, 1988). **This project demonstrated that children who had been adrift in foster care for long periods of time could be returned to their biological families or placed in adoption through intensive agency planning and casework.** Permanency planning first was emphasized in federal law with the passage of the Adoption Assistance and Child Welfare Act of 1980 (Public Law 96-272), which established fiscal incentives to states and procedural reforms to provide family-based services and prevention of out-of-home placements.

The Child Abuse, Domestic Violence, Adoption and Family Services Act of 1992 was signed into law on May 28, 1992. Listed as Public Law 102-295, this Act reauthorizes federal Child Abuse Prevention and Treatment Act programs. Its primary focus is on the improvement of state child protective service systems. Under Title I of the Act, a new section on Findings was added to the Act that:

- emphasizes family preservation services and strengthening families to remedy the causes of child abuse and neglect;
- provides support for intensive services to prevent the unnecessary removal of children from families; and
- promotes the reunification of such families if removal takes place. (Social

Legislation Information Service, 1992).

States are also required, under Title I of the Act, to spend not less than 50 percent of Community-Based Prevention Grants Program funds to support community-based child abuse prevention programs.

Taylor, et.al., (1989) suggested that **when states or agencies intervene with children and their families, permanency planning should be their guiding philosophy**. As Taylor, et.al. (1991), observed, **"as the experience in child welfare indicates, however, permanency planning can become an empty bureaucratic exercise if not accompanied by a philosophical commitment to supporting a family's relationship with its child."** (pg. 17)

Taylor, Bogdan, and Racino (1991) feel that the closure and downsizing of public facilities and the simultaneous growth in the number of persons placed in private facilities has resulted in the phenomena that they refer to as "transinstitutionalization," or the shifting of persons or the responsibility of care from one institution to another. As a matter of fact, during the same period that the population of large, state operated ICFs-MR declined by 29,815, from 1982 - 1990, the population in private ICFs-MR (of all sizes) increased by 30,615, with 9,581 of those persons now living in private ICFs-MR with capacity for 16 or more persons (Lakin, 1992).

Alternatives to Out-of-Home Congregate Child Care

Increasingly, children with intense medical needs, as well as children with severe developmental delays and/or physical disabilities, who are placed out of their natural homes, have been seen as good candidates for foster care and adoption. This trend toward foster care and adoption has developed as a part of the shift in the philosophy of providing supports and services to families rather than to children and youth in out-of-home placements. In describing the state of Michigan's commitment and approach to permanence planning, Taylor, et.al. (1991), list four major options in out-of-home care that are often pursued there:

> One option is termed "shared care," an arrangement in which the natural and foster parents agree to share responsibility for the child (e.g., weekdays at the foster home and weekends with the natural family).
>
> Another option is permanent foster care. This a nonlegal arrangement by foster families to serve as primary parents for a child until adulthood.
>
> A third option is adoption. Macomb-Oakland stresses this option when birth parents avoid involvement with their children. In Michigan, adoptive families can qualify for subsidies, including a foster care payment and **either** a medical care subsidy (determined by the child's needs) **or** the state's family support subsidy ($2,700 a year). Places such as Macomb-Oakland look to foster families for adoption. *(Emphasis and information in the parentheses is the Illinois Planning Council's).*

> A final option is called "open adoption," a nonlegal arrangement whereby a family puts a child up for adoption, but the adoptive family agrees to cooperate with the birth parents' continuing involvement. (pg. 23)

Halfon, Berkowitz, and Klee (1992) note an increasing trend toward foster care placement. Citing the Select Committee on Children, Youth and Families (1989), they state there were 340,300 children in foster care in the United States in 1988; this number was projected to exceed 500,000 by 1995. They studied Medicaid utilization by children in foster care in California, observing that in California, the number of foster children more than doubled from 27,534 in 1980 to 62,419 in 1988, then increased to 78,221 in 1990. These increases in the number of foster children represent growth of 151% from 1980 to 1990, suggesting that utilization of foster care is a viable alternative to public or private institutionalization.

Taylor, et.al. (1991), detail the approach a Michigan state agency, the Macomb-Oakland Regional Center (MORC), has taken in developing specialized foster families even for children with the most severe multiple disabilities and medical involvements. Foster home recruitment is a top agency priority. MORC employs three full-time community training home specialists who recruit, screen, and train foster parents. The agency aggressively recruits foster parents through public service announcements, newspaper articles, radio and television appearances, community presentations, flyers, posters, classified advertisements and referrals from other people. This recruitment effort generates thousands of calls that are screened to find a few good families to provide foster care. The agency pays these foster families fairly well ($25-$35 per person per day) and higher in some cases. MORC supports these families by providing: respite care, professional consultation (nurses, occupational therapists, behavior analysts), home aides, financial assistance for special equipment, and necessary home modifications. Michigan's approach to permanency planning also treats foster families in the same way that natural families are treated -- offering foster families the same components of family support that are provided to natural families in preventing out-of-home placements. MORC case managers maintain frequent contact with the families, visiting at least monthly and making unannounced visits on occasion. Whereas Macomb-Oakland used to develop group homes for children, this is no longer done -- **all children, including those with the most severe disabilities, are placed in foster care.**

Nisbet, Clark and Covert (1991), describe several exemplary adoption programs for children with disabilities:

- **Project IMPACT** is a placement agency for children with "special needs" in Massachusetts. It has coordinated an interagency effort to promote permanency planning for children since 1984.

- **The Rocky Mountain Adoption Exchange** involves permanency training for interdisciplinary teams for developmental disability service providers, foster care and adoption agencies, community-centered boards, legal services, and advocacy and parent groups.

- **The University of Kansas--Children's Rehabilitation Unit** assists with adoption and provides service facilitation to families after the placement.

- **Project S.T.A.R.** in Western Pennsylvania, has a Specialized Parent Preparation program that offers families an opportunity to explore their attitudes about and to learn more about disabilities, parenting and adoption. This project has produced a recruitment video titled, "Straight from the Heart."

- **Michigan's Specialized Adoption Program** has received national attention for its successful use of permanency planning for children with developmental disabilities and children with mental health needs. The program offers counseling of birth families concerning their decision to give up children for adoption, assessments, recruitment and adoption work for each child, and post-release and post-adoption services.

Public Law 102-295, described above, also strengthened the role of the federal government in promoting the adoption of children with disabilities. The statement of purpose for Adoption Opportunities (Title IV of the Act) has been revised to:

> specify that it is intended to facilitate the elimination of barriers to adoption and to provide permanent home environments for children who would benefit from adoption, particularly children with special needs, including . . . infants (with disabilities having) life-threatening conditions by:
>
> - promoting model adoption legislation and procedures in the states;
>
> - promoting quality standards for adoption services;
>
> - pre-placement, post-placement and post-legal adoption counseling, and standards to protect the rights of children in need of adoption;
>
> - maintaining a national adoption information exchange system; and
>
> - demonstrating expeditious ways to free children for adoption. (Social Legislation Information Service, pg. 143).

The Secretary of the Department of Health and Human Services has been directed, under Title IV of the Act, to maintain a National Resource Center for Special Needs Adoptions. This Resource Center (16250 Northland Drive, Suite 120, Southfield, Michigan, 48075) has an extensive publication list that includes information on adopting children with disabilities, permanency planning and suggestions for professionals working with adoptive families.

Discretionary grants offered under the Adoption Opportunities program of the Act included requests for applications (that were due August 15, 1992) under the following priority areas:[1]

(1.11) Achieving Permanency for Children in Relative Foster Care,

(1.12) Assistance for Children in Residential Group Care to Obtain Permanent Homes,

(1.13) Adoptive Placement of Foster Care Children,

(1.15) Recruitment of Military Families for Adoption of Special Needs Children,

(1.16) Recruitment of Rural Families for the Adoption of Special Needs Children, and

(1.19) Field Initiated Proposals To Improve Adoption Services to Children with Special Needs.

[1] Despite offers of assistance from the Illinois Planning Council staff, the Illinois Department of Children and Family Services chose not to pursue an application for any of the grants in this list.

Developing Community Service Networks

The sixteen major recommendations of the 1977 National Conference on Institutional Maltreatment of Children included:

- encouraging private, competing agencies -- **not the government** -- to develop community child services,
- insuring that those agencies are answerable to the communities in which they are located; and
- developing voucher systems -- money that moves with each child -- rather than providing funding directly to child care institutions or foster home agencies.

In 1989, the Child Welfare League of America (CWLA) produced a report and recommendations related to out-of-home care, that echoed the 1977 conference recommendations. The report presented a series of "challenges", and the recommendations suggested strategies for addressing the challenges. Challenge #4 was, **"Out-of-home services should operate as part of a comprehensive, coordinated system of services that support children and their families."** (pg.13) The report goes on to say,

> The current community system of services for children and families, however, is most often better described as a nonsystem. **Categorical programs have led to categorical agencies, each claiming some, but not exclusive, responsibility for providing a part of what is required by children and families in need.** Further, the relationships between the relevant provider agencies, including child welfare, education, health, mental health, housing, and juvenile justice, are often nonexistent or competitive. Services that

do exist often become inappropriately used due to the absence or unavailability of other, more appropriate ones. Additionally, even within a single agency, referrals to different programs frequently are as complicated and time-consuming as if the child were being referred to another agency.

Service integration, necessary to meet the diverse and changing needs of children and their families, too often is missing, both among and within provider agencies. (pgs. 13 & 14)

The strategies developed by the CWLA to address these findings included:

- promotion of successful models for service integration;
- comprehensive needs assessment and planning involving private agencies and all levels of government;
- establishment of local coordinating bodies;
- using qualified staff to conduct individual family assessments and interventions, with maximum involvement of parents and older children; and
- expanding service options to effectively respond to child and family needs.

Another challenge in out-of-home care identified by the CWLA is **making agencies responsive to the community from which children come.** To become more responsive, the CWLA stated that, "agencies must use an active process with parents to help eliminate the problems that led to the placement of their children. In addition, that services are necessary to promote the successful postplacement adjustment of children in their families and communities is now recognized as critical to successful practice." (pg.15) In effect, this means that **agencies providing residential services for children must become "providers of family support services, not . . . a substitute for them."** (pg. 16) In order to do this, **out-of-home care agencies need to "become culturally competent and relevant to minority . . . communities."** (pg. 16) Social service agencies have not been effective in meeting the needs of minority children (especially African-American, Latino-American and Native American children). As Williams and Sipp (1988) observe, "despite changes in policy and practice that focus on the prevention of placement, family reunification, and permanency planning, **children of color continue to be overrepresented in out-of-home care, to remain in care longer, and to be less likely than the majority children to have their lives stabilized through adoption."** (pg. 154)

Congregate Residential Child Care Facilities

Residential child care facilities tend to have a type of service in which they specialize, but almost all such facilities serve children having a variety of needs, conditions or patterns of challenging behavior. This tempts child welfare agencies to use whatever services are available, due to the

absence or unavailability of other, more appropriate services. The inappropriate use of specialized facilities (also cited above by the Child Welfare League), was found by two national surveys conducted by the University of Chicago (Young, Dore, Pappenfort, 1989). These surveys found that significant numbers of children and youth with mental retardation resided in nearly every type of childrens' residential facility listed, as shown in Table 1 (next page). Please note that the totals listed in the table are given only for those facilities that identified specific referral reasons, conditions, in the surveys: the total number of children and youth placed in residential facilities that responded to the 1981 surveys was about 125,000 children.

It should be noted that facilities identified the following referral reasons, conditions and patterns of challenging behavior as existing *in every type of facility* (presented in order from most to least prevalent): family problems, peer relationships, disruptive behavior, accused and adjudicated delinquent, depressed, destruction or theft of property, abused, learning and perceptual problems, violence toward others, inappropriate sexual behavior, thought disorders, violence to self, suicidal, mental retardation, chronic physical problems and drug or alcohol abuse. With such heterogeneous groupings, providing residential care in such facilities is very complex and very difficult. Persons with mental retardation placed in such facilities are exposed to role models from whom they will learn behaviors that will make it even more difficult for them to return to their natural homes or for them to succeed in an adoption or foster care placement.

Young, Dore and Pappenfort note, in the conclusion to their report:

> The shift in 15 years (from 1966-1981) to smaller facilities is change of a magnitude not ordinarily encountered in such a relatively brief period of time. The findings suggest that recent emphases on deinstitutionalization, permanency planning, and normalization have brought forth the beginnings of a transformation in the field of residential group care . . . Staff-to-resident ratios (in 1981 were) better than they were (in 1966); substantially larger proportions of children in most types of care are attending school in the community rather than at the facility; and family involvement in the programs of care appears to be becoming the rule rather than the exception . . . The stereotype of large, remote, and barren institutions no longer applies for most facilities for children . . . We have observed that average lengths of stay at all types of facilities have declined markedly . . . It may be that, in some places, residential group care is becoming one brief point on a temporal continuum of care or service -- a point both preceded and followed by a range of nonresidential services to children and their families. To frame the issue more sharply, **more residential group care facilities are caring for more difficult children for briefer periods of time; the question for the near future is whether preventative and follow-up services are to be made available and coordinated with admission and return from group care, when necessary**. (pgs. 33-34)

Table 1

1981 Residential Placements of Children and Youth with Mental Retardation in the United States

Type of facility	Total # of Children and Youth Served in type of facility	Percent having mental retardation	Number of children and youth with mental retardation
Dependent and Neglected	22,937	6	1,376
Pregnant Adolescent	1,453	8	116
Temporary Shelter	3,692	7	258
Delinquent	37,606	10	376
Status Offender	3,734	6	224
Detention	14,027	8	1,122
Substance Abuse	1,495	2	30
Emotionally Disturbed	19,116	10	1,911
Psychiatric	12,292	12	1,475
TOTALS	116,352	9	10,273

Concerns with Abuse in Institutions

One of the main worries parents and advocates have about placing children and youth in congregate care facilities is the potential for abuse by staff members of these facilities. A survey investigating institutional abuse was mailed to of 166 Child Welfare League member agencies in the summer of 1986, yielding 100 completed questionnaires (DiLeonardi & Kelly, 1989). The responding agencies represented all areas of the country and among them provided care for 10,000 children. During the two years preceding the survey, there was a total of 346 allegations of physical abuse and 136 allegations of sexual abuse. This produces a rate of 48.2 allegations per one thousand children in residential care settings. According to the reporting agencies, 23.2% of these allegations were found to be valid. It should be noted that 25% of the reporting agencies only performed internal investigations of allegations (not reporting them to legal authorities in their states); in most states, the child care professionals are "mandated reporters" -- they must report every suspicion or allegation to their state's child protection agency.

The types of physical abuse reported in the survey included allegations of staff: striking children (38%); using excessive force in subduing children (20%); using extreme force, such as breaking a child's arm (15%); and a variety of other charges, such as staff: leaving a unit unsupervised,

allowing children to hurt each other, etc. These alleged acts of physical abuse were committed mostly by direct service staff (child care workers and house parents). The types of sexual abuse reported included rape or intercourse with children (25%); sexual fondling (46%); and verbal sexual harassment. Fifty-four percent of these incidents were heterosexual acts; 36 percent were homosexual. Unlike the incidents of physical abuse, in which direct service staff were responsible for 95% of the allegations made, direct service staff were accused of committing only 63 percent of incidents of sexual abuse. Foster parents, administrators, or other professionals were alleged to be responsible for committing the remainder of these acts.

While the focus of this paper is on providing family support and out-of-home care consistent with the principles of permanence planning, it is important to recognize that **safeguards must be introduced or strengthened to protect children and youth currently residing in institutional and foster care settings**. The agencies responding to the DiLeonardi and Kelly survey were asked how they attempted to prevent abuse from occurring and how they might improve these procedures. The four major strategies suggested by the agencies for abuse prevention centered on improving staff selection, management of behavior in a group care setting, supervision of staff, and reporting procedures. **The most important general recommendation was that agencies should develop a low threshold culture for child abuse,** meaning that agencies must communicate, at all levels, that abuse will not be tolerated and that agencies must implement comprehensive policies to prevent abuse, investigate allegations of abuse and where warranted, pursue legal action against caregivers and professionals suspected of abuse.

Key recommendations for staff selection procedures that prevent abuse included:

1) careful investigation of previous employment history, personal and background references, a police check and Child Abuse Registry check of prospective employees;

2) use of psychological tests, such as the MMPI or the California Psychological Inventory, to identify applicants who might be potential abusers (the instruments selected should have validity for this purpose -- research studies should be reviewed by qualified professionals to determine whether the tests selected can adequately predict the risk profiles of persons likely to become abusive);

3) use role-playing procedures that expose job applicants to simulated anger and hostility from children; and

4) written personnel policies that allow immediate suspension and dismissal of an employee who is alleged to have abused a child and cooperation with authorities if legal action is pursued by them.

Key recommendations for behavior management included:

1) teaching staff to use crisis intervention skills, in order to avoid confrontations and to deal

with children whose behavior is out of control (as well as to help the staff member retain control of his or her behavior);

2) teaching staff to use safe passive restraint procedures, to use when children present a clear danger to themselves or others; and

3) avoiding isolation of a staff member with a child in crisis.

The three recommendations for supervisors to use in preventing abuse were:

1) documenting and reviewing the progress of children carefully to look for patterns that indicate possible problems of children with particular staff members;

2) supervising each child care worker and professional staff member individually, including the use of on-site observation of interactions between staff and children; and

3) avoiding the promotion of special staff-child relationships, in the absence of careful team planning (such relationships might lead to unplanned and potentially abusive visits by children to the homes of staff members -- a policy should be established that strongly prohibits unplanned visits).

Regarding incident documentation, it was recommended that agencies should:

1) use a critical incident reporting system that includes comprehensive written reports of all situations involving children and staff, whether they be accidental or not, by all those who were involved in the situation -- these reports should then be summarized and a written description of the incident provided to the state's Child Protective Agency; and

2) deal honestly and openly with parents and others involved in abuse complaints -- as soon as the facts are ascertained, the parents or guardian of the child should be told exactly what is known by the agency.

DiLeonardi and Kelly did not mention another very important strategy for developing staff behavior management skills -- to teach staff members to use positive behavior management to promote prosocial behavior in children and thus, **to avoid crisis situations**.

Rindfleisch and Rabb (1984) found rates of complaints of child abuse in residential institutions similar to those reported in DiLeonardi and Kelly's survey. They reviewed another national survey conducted in 1980, in which surveys were mailed to 1,700 residential facilities. The Institutional Child Protection Project (ICPP) at Ohio State University received completed surveys from 1,100 facilities, housing 69,271 children. The survey found that the average rate of abuse complaints, across all geographic regions, was 39 per 1,000 residents. After the survey results were obtained, the ICPP staff made follow up site visits to 12 facilities in four states to validate the findings of the survey and to document child protection practices and experiences. Overall,

they found complainable occurrences to be greater than the numbers reported by the survey in the four states observed. Rindfleisch and Rabb **believe that the ICPP's survey results demonstrated that there was substantial underreporting of complainable occurrences in these four states.** The child protection practices that contributed to this underreporting included variations in the way incidents were investigated across and within facilities; lack of clarity about what constituted mistreatment; direct service staff "handling" incidents informally; administrators dealing with incidents as a staff performance problem rather than as an infringement on the rights of the children; and failure of administrators to report incidents to outside authorities and agencies.

By way of comparison, Rindfleisch and Rabb contrasted the survey data from the ICPP and another study with the incidence of reported child abuse in family settings. **Even with the underreported rate of 39 per 1,000 children served in residential facilities, the facility rate was more than twice as large as the reported rate of occurrence of abuse in families (17.8 per 1,000 children).**

Family Support

Historically, Illinois first responded to some of the needs of some natural families by offering respite services funded by the Department of Mental Health and Developmental Disabilities (DMHDD); these services continue to the present day. According to Louro, et.al. (1987), pilot projects in Illinois for family support began in 1977. DMHDD and the (then) Governor's Planning Council on Developmental Disabilities co-funded a project operated by Aid to Retarded Citizens, in Springfield, that offered counseling and service facilitation. This led to the creation of Family Support Units with similar functions in local Associations for Retarded Citizens throughout the state. Later, a statewide development of Case Coordination Units took place, with many of these Units assuming these "family support" responsibilities.

The Planning Council has been instrumental, in piloting Family Support programs that went beyond counseling and service facilitiation. The pilot projects offered a full range of services, supports and cash stipends, to families in various locations around the state. In 1989, four pilot projects were funded by the Council in Chicago, LaGrange, Rockford and Jacksonville. Each of these pilot programs provided support to families via information and education that: **helped families to obtain needed supports; arranged for future planning** to promote the development of long range plans for the family member with a disability; and **established a financial assistance program** that provided families with direct cash payments to purchase needed supports (Agosta, et.al., 1991). Approximately 165 families were served by the 1989 pilot projects, with 95 of the families having a family member with a disability aged 0-21. Sixty-six of the 165 families reported receiving cash assistance during the pilot projects that was used "principally on behalf of the family member with a disability for medical services or insurance, transportation, recreation, adaptive equipment and housing adaptations." (pg. 48) These pilot programs were also subsequently funded by the Department of Mental Health and Developmental Disabilities. In both the early efforts in family support and in the more current efforts, **evaluations have consistently found the annual cost to the state of providing these services to prevent institutionalization was more cost effective than providing institutional residential services, either at state operated facilities or in private ICFs-MR.**

The first comprehensive, statewide attempts by Illinois to provide financial support directly to families, in order to prevent out-of-home placement of children, began with the passage of Public Act 85-938, the Family Assistance & Support Program. This program provides reimbursement to families for special adaptive equipment, minor structural modifications to a residence or vehicle, adaptive clothing, medications, special diets, transportation to special services and other unusual expenses deemed necessary to maintain a person with severe or profound disabilities at home. The program provides up to $2,500 a year reimbursement per family for these services (except when this limit was waived by the Department of Mental Health and Developmental Disabilities in cases of extraordinary need) and "was intended to assist families who cared for individuals who were severely or profoundly developmentally disabled, with the expressed intent of preventing or delaying the institutionalization of these family

members or returning them to the home setting." (Fujiura, Garza, & Braddock, 1990, pg. 20). According to a DMHDD staff member (Sims, 1993), this availability of this program was not advertised to families directly. Instead, the Department received requests for funding through community agencies for families in extraordinary need and these funds were allocated on a first-come, first-served basis. The funds allocated for this program were depleted more quickly than expected and there has been very little turnover in the families using this program to help meet their needs; because of staff shortages at DMHDD, there has not been an effort to conduct utilization review of these funds (or a proposal to expand this program) in order to make it available to more families.

In 1989, the enactment of the Family Assistance Law for Mentally Disabled Children (Article III of Public Act 86-921) gave the Department of Mental Health and Developmental Disabilities more flexibility in meeting family needs. The purpose of this law was, again, to "strengthen and promote the family and to prevent out-of-home placement of mentally disabled children." It provided for a monthly cash stipend that was provided to a limited number of families -- although the Department received approximately 3700 applications for the cash subsidy from parents of children with developmental disabilities, only 284 were selected by a computer drawing for the subsidy (a 1992 letter from the Parents for Inclusive Communities referred to the selection process as a "'lottery' system that really was a 'luck of the draw'"). The evaluation of this program conducted by the University of Chicago (Goerge, et.al., 1992) found that the **cash stipends were helpful in preventing or delaying out-of-home placement plans.** Children in the group that did not receive stipends were at higher risk for out-of-home care.

Both of these Family Support programs (P.A. 85-938 and P.A. 86-921) have been funded entirely through the state's General Revenue Fund. Table 2, on the next page, shows that the actual spending on these programs has been consistently lower than the appropriations by the Legislature. These spending patterns were detailed in the Governor's FY 1993 budget proposal and confirmed in a letter from DMHDD to service providers (Sims, 1992). Reasons for this gap between appropriations and spending include the state of Illinois' ongoing fiscal difficulties (the lapse of funds in the Fiscal Year 1992 budget cuts); time needed to establish procedures, for families with children and youth; and time needed to do additional assessments and program planning for families with adults who received funding. DMHDD cut approximately $2 million from the Public Act 86-921 budget in January, 1992, closing enrollment in the program for the remainder of the fiscal year. This budget cut was described by the Department as a "managed lapse;" DMHDD's rationale for making these cuts in the family support program was that it was one of "several lines (that) had available balances that were not fully committed." (State of Illinois, 1992A, pg. 2). The managed aspect of the cuts is evident in the Department's explanation of the reduction of the CILA budget: "as we became aware that funds would not be fully spent, new contract capacity was not awarded because of anticipated midyear cuts . . . Public Act 86-921 (funds were) projected to lapse about $2.0 million, also due to late enrollment." Thus, the Department made a conscious decision <u>not</u> to enroll persons eligible for the program, in order to give priority to other programs; applying "numerous cost saving approaches before cutting <u>agencies</u>' direct services."

The Association for Retarded Citizens of Illinois (Curtis, 1992) made the following comments about the family support budget cut:

> BUDGET CUT: PA 86-921, or HB 69, received one of the biggest proportional hits in the entire budget package. The 37% cut, again labelled lapsed funding, because it looked like it wasn't going to be spent, is a devastating blow to the program.
>
> IMPACT: Again, the danger is making the assumption that the program isn't needed. This is an ironic and clearly incorrect statement when more than 7,000 applications from families across the State are begging for assistance . . . The most serious danger, however, is the recognition by the administration that this consumer driven program, highly touted by Illinois when it was passed, appeared to be an easy mark for the cuts . . . Average payment in this program is $675 per eligible individual with developmental disabilities. The $2 million cut, translated into actual impact to families, is nearly 3000 families could have been served with the lapsed dollars. (pg. 4).

Table 2

Funding for IDMHDD Family Support Programs
(Corrected from *Illinois -- It's 1992*)

APPROPRIATIONS FOR FAMILY SUPPORT PROGRAMS	FISCAL YEAR 1991		FISCAL YEAR 1992		FY 1993
	Appropriation Authority Actual	Expenditures Actual	Appropriation Authority Actual	Expenditures Actual	Appropriation Authority Actual
Family Assistance and Support (reimbursement) -- Children (85-938)	(Not available)	(Not available)	$609,600[2]	$609,600	$609,600
Family Assistance Programs (cash subsidy) -- Children (86-921)	$1,562,400	$705,900[1]	$1,454,600	$1,202,500	$1,298,000
Home-Based Programs -- Adults (86-921)	$3,330,800	$572,300[1]	$3,583,000	$1,788,800	$2,869,800

Table Notes

1. ***The 1992 University of Chicago evaluation by Goerge, et.al., suggests an explanation for the large discrepancy between the amount appropriated vs. expended for this program, saying that the program had not achieved full enrollment until the ninth month of the first year of the program. The authors of the study***

attribute the delay to "the unforeseen amount of time needed to process the applications and the extra time families needed to submit the necessary documentation."

2. *The appropriation for this program is part of the budget line item titled "Child and Adolescent Programs for DD." The full appropriation for this line item is $961,800 for SFY 1992 and 1993. $609,600 is allocated for the PA 85-938 (DMHDD Code 91W) reimbursement program (Rachunas and Armitage, 1993).*

Table 3

Families Currently Being Served by IDMHDD under Family Support Programs

Program Title	Number of families of persons with developmental disabilities[1]	Number of families of persons with mental health needs[1]	Total
Family Assistance (85-938)[2]	46	--	46
Family Assistance/ Children (86-921)	168	57	225
Home-Based/Adults (86-921)	214	125	339

Table Notes

1. *The numbers presented here are as of 1/26/93.*

2. *This program has been frozen at it's present level for two years (Rachunas & Armitage, 1993).*

A Family Support Network project was funded by the Planning Council and began to function on April 6, 1992. A letter from the Parents for Inclusive Communities (1992), recruiting parents to participate in the Family Support Network, stated that the purpose of the Network is to provide training and advocacy "to give families courage and confidence to obtain assistance from their local legislators and public decision makers, enabling them to keep their family members within the family and not be at risk for placement outside the home." One of the stated goals of the Network is to expand on the Family Assistance and Home-Based programs.

The Department of Children and Family Services (DCFS) began a Foster Care Initiative several years ago that was mentioned by the General Accounting Office (1989) in their report on foster parent recruitment and preservice training. The DCFS Foster Care Initiative was also described in the Department's 1990 *Human Services Data Report* as an effort "to revitalize, improve and upgrade Illinois' foster care system." (pg. 72) The *Report* goes on to list the following actions

that were taken by the Department as a result of this Initiative:

- clear and concise statements defining the roles and responsibilities of foster parents, foster parent support specialists, direct service workers and resource development staff have been developed;

- strategies for recruiting appropriate persons to serve as foster parents have been initiated;

- a series of training curricula targeted to all members of the foster care service delivery team have been used to train trainers, foster parents and Department staff; and

- strategies for providing foster parents with a stronger support system have been identified and are in the process of being implemented. (pg. 72)

It is the understanding of the Planning Council that, despite the state-of-the-art concepts that were developed and implemented under the guidance of a Statewide Foster Care Advisory Committee and foster parent association, the Initiative was never fully funded. Estimates of the cost of full implementation are about $20 million. In addition, many of the lay off notices given out by DCFS in August, 1992, were targeted at reducing the number of direct-service workers that "handle resource development and licensing, foster-home placement and adoption, and programs for children with special needs." (McGhee & Gerber, 1992) Thus, with changes in the internal structure of the agency and the length of time that has passed since the advocacy, research and other work originally was done, the continued viability of the Foster Care Initiative is called into question.

The Illinois Division of Specialized Care for Children plays a significant role in assisting eligible children in remaining at home, both through the Division's core program of service facilitation and through its Home Care program, in which approximately 200 medically fragile children may receive services in their family homes. The Home Care program is funded by a Medicaid waiver program that stipulates that the cost of caring for children at home must be less than that of care in a skilled nursing facility or a hospital.

Out-of-Home Placements

Available data from various state agencies show that there are significant numbers of Illinois children with disabilities in out-of-home placements (either in small, family-scale placements or in larger, congregate care facilities). The Illinois State Board of Education reports reimbursement for special education provided to children in out-of-home placements: **2,650** children claimed individually and for **2,700** children in group programs in their Fiscal Year 1993 Budget Proposal. Information provided by the State Board to the Community and Residential Services Authority indicate that, in the 1990-1991 school year, there were 25,673 children receiving services for behavior or emotional disorders. Of these, **1,236** were in out-of-home

placements within the state; **541** were in out-of-state residential placements (Schornagel, 1992).

Information from the Data Report of 1991 showed the Department of Children and Family Services lists the following numbers of children and youth, as of December 31, 1989:

- **7,472** in homes of relatives,
- **9,389** in foster care homes (excluding children in pre-adoptive foster homes),
- **325** in group homes, and
- **2,342** in institutions.

In information provided to the Community and Residential Services Authority, DCFS reported that **1,733** of these children were in out-of-state placements (Schornagel, 1992). Schornagel (1992) suspects that most of these children are residing in foster care in the homes of relatives in states immediately adjacent to Illinois. DCFS does report a total of **197** children who were identified as having one or more "handicaps" who the Department lists as "free for adoption" as of December 31, 1989. Children identified as having "handicaps" include those listed as having a behavior disorder, education handicap, mental impairment, physical health impairment, or a multiple impairment.

In February, 1993, the Illinois Department of Children and Family Services provided additional information about the number of children with developmental disabilities residing in group homes and institutions. The Illinois Department of Children and Family Services (IDCFS) was authorized by the Illinois Legislature and Governor to spend $93,366,000 in State Fiscal Year 1993 on the 3,588 IDCFS wards residing in group homes and institutions (including children who were abused/neglected, who were adjudicated as delinquents, and who were identified as having disabilities). IDCFS is planning to ask the Legislature for a supplemental appropriation for spending on group home and institutional placements because they project the amount needed for the remainder of this fiscal year for these out-of-home placements will be more than $100,000,000. (In SFY 1992, IDCFS spent $105,300,000 on these placements). A detailed breakdown of the number of children with disabilities living in group homes and institutions is given in Table 4, on the next page.

By extrapolating from the spending for all children in IDCFS-funded group home and institutions, it is estimated that the average cost of this out-of-home care is about $30,000 a year. The estimated annual cost of serving 592 children at the extrapolated spending level is $17,760,000.

The Illinois Department of Mental Health and Developmental Disabilities funds three types of out-of-home placements for children and youth -- those for institutional services provided by state-operated facilities, in-state "purchase of care" and out-of-state purchase of care. Out-of-state purchase of care is reserved for persons who IDMHDD has assessed as having needs that

cannot be met by public or private service providers within the state. IDMHDD reported the figures for Fiscal Year 1992, presented in Table 5, on the next page, to the Community and Residential Services Authority (Schornagel, 1992). Regarding the numbers of children and youth receiving residential services, Schornagel reports that the Department of Mental Health and Developmental Disabilities stated that of the 900 persons funded for residential services through purchase of care, approximately 12% were over age 21. The number of children and youth with developmental disabilities, ages 0 - 18 who lived in facilities operated by the Department of Mental Health and Developmental Disabilities was only **96** for Fiscal Year 1992 (State of Illinois, 1992B). IDMHDD operates public ICFs-MR that provide residential services to adults and these children. Budget information provided to the Illinois Planning Council on Developmental Disabilities by IDMHDD (Kimmel, 1993) reveals that the operational and central

Table 4

Institutional and Group Home Placements (IDCFS-funded)

Children with Developmental Disabilities (Federal Definition) Identified by IDCFS through School Program (SP) and Handicap (H) Codes[1]	**Number of Children[2]**
Special Class for Emotionally Disturbed (SP), Behavior Disorder (H)	336
Educable Mentally Handicapped (SP), Trainable Mentally Handicapped (SP), Mentally Impairment (H)	163
Special Class for Multiply Handicapped (SP), Multiple Handicap (H)	93
TOTAL	592

Table Notes

1. ***The codes appearing in the table and the data were provided to the Council by IDCFS on 2-09-93 (IDCFS, 1993). This table excludes children who were assigned codes that indicated they received special education for a learning disability (defined by their performance on an intelligence test that places their score above 2 SDs below the mean IQ score and their experience of significant difficulties in specific academic skills or psychological processes), children who were identfied as blind, deaf, blind and deaf, or as solely physically handicapped.***

2. ***The numbers presented here are as of 1/31/93.***

office administrative budget for State Fiscal Year 1993 for these facilities totals $259,700,000 (this figure includes the share for state-operated facilities serving all persons with developmental disabilities from the general revenue fund, Medicaid Title 19 reimbursement and all other funds).

The total facility census in public ICFs-MR, as of 11-30-92 was 4,273. IDMHDD is currently down-sizing these facilities, so it is difficult to extrapolate the costs of serving these individuals, but if the same method was used as for IDCFS- and DPA-funded services, the annual cost of serving an individual in a state-operated facility would average about $60,000. It should be noted that this is nearly twice the cost of services provided by the other Departments because IDMHDD included some administrative costs. It is believed that the other Departments did not allocate the costs of central office management, nor are the costs of survey and inspection of care of those facilities included. Actual costs to the state of serving persons in IDCFS- and IDPA-funded facilities may also be substantially underestimated in the sections above.

Table 5

Persons Funded for Residential Services by DMHDD[1]

Placement & Grant Type/Disability	Number of Children and Youth
In-state, Purchase of care/developmental disability	698
In-state, Individual care/mental illness	133
Out-of-state, Purchase of care/developmental disability	202
Out-of-state, Individual care/mental illness	43
In-state, State-Operated Facility for DD	96
TOTAL	1,172

Table Notes

1. ***These figures are for State Fiscal Year 1992.***

2. ***The budget figures for serving persons in these placements have not yet been obtained by the Planning Council.***

In addition to the out-of-home placements cited in the preceding information, it should be noted that the Illinois Department of Public Health reports licensed capacity for Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) serving children and youth (ages 0 - 21) as **1,098** as of June 1, 1992. A list of these facilities can be found in Appendix B in this paper. The average annual cost for serving a person in an ICF-MR in Illinois is $31,524 (Lakin, 1992); the actual cost of serving children and youth may be higher, as the IDPA facility reimbursement system is tied to the program and service needs of the children and youth living in the facilities. By contrast, the IDCFS facility reimbursement system does not provide additional funding over

the basic per diem tied to the identified needs of the child. (See the next section on the key informants for more information on this issue). Also, as noted above, this average does not reflect administrative costs of licensure surveys (performed by IDPH) or quality assurance/inspection of care (done by IDPA). The total estimated cost of placements for 1,098 children at the average annual cost would be $34,587,000, excluding these administrative costs. Additional facts about ICF-MR placements for children and youth:

- **The average size of these Illinois facilities is 86 children per facility. This is almost triple the national average size of child care institutions of ten years ago, as reported in the survey conducted by Young, Dore, & Pappenfort (1989) -- this average size is significantly greater than that noted under national trends for children's institutions.**

- **The average size of Illinois facilities serving children is also much higher than the national average size of private ICFs-MR.[2] Lakin (1992) reports that as of June 30, 1990, 75% of privately-operated ICFs-MR in the nation had capacities for no more than 15 people.**

- **Nationwide, facilities with no more than 15 persons served 47% of the persons residing in all privately-operated ICFs-MR (Lakin, 1992).**

- **Even when an average facility size is calculated for all private facilities (including larger facilities), the overall average number of persons served in both smaller and larger private ICFs-MR is 14.**

- **The average annual cost for serving a person in an ICF-MR in Illinois is $31,524 (Lakin, 1992) -- more than ten times the amount a single family would be eligible to receive under the state's Illinois family support programs, if these programs actually were available to all eligible families.**

- **Illinois' spending on Intermediate Care Facilities for the Mentally Retarded is low, by national standards, ranking as the fifth lowest cost per person in the United States, after West Virginia, Wisconsin, Mississippi and Hawaii (Lakin, 1992). These costs to the state can only be expected to escalate dramatically, especially if federal agencies repeat the "Look Behind" surveys done in Illinois in 1986 and 1987, in which the federal surveyors disqualified about 50% of the beds in the state from receiving federal matching funds.**

- **The aggregate cost for serving 1,098 children and youth, the capacity of private ICF-MR licensed facilities in Illinois funded by the Department of**

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[2] ***The data reported by Lakin does not indicate how many of these facilities serve children vs. how many serve adults.***

Public Aid, is over $33.5 million. This is more than 11 times the amount of money IDMHDD reports was spent during FY 1992 for the family support programs serving families of children and adults, and does not include the costs of institutional care funded by IDMHDD or IDCFS.

The fact that so many Illinois children with disabilities reside in large, congregate care facilities calls into question the basic value system underlying the provision of services to children and youth with disabilities in Illinois. The overwhelming disparity between the state's spending on family support and spending on large, congregate, out-of-home care demonstrates the need for a basic reevaluation of the state's existing values and policies with respect to serving its children and youth. Moreover, as detailed in the survey deficiencies listed in Appendix C, large facilities are much less capable than adoptive or foster families or family-scale homes of responding to the individualized needs of the children and youth living in them.

Illinois Residential Care Key Informant Interviews

In July, 1992, the Illinois Planning Council on Developmental Disabilities conducted several structured phone interviews to identify current issues from the standpoint of providers of residential services to children with developmental disabilities. Ron Moorman, Executive Director of the Illinois Child Care Association, nominated five individuals for these interviews, four of whom were contacted during the week of July 12. These individuals were employed by the following agencies: Catholic Social Services of Chicago, Glenkirk, Goldie Floberg Center, and Lutheran Social Services of Cook County. All but Lutheran Social Services operate residential facilities for children with developmental disabilities licensed either by DCFS or by DPH. Lutheran Social Services was the only agency that offered supervised foster care. Three of the agencies offered service facilitation. All four agencies offered interdisciplinary assessment, program planning and crisis intervention services. The following additional services were offered by individual agencies: early childhood education; specialized foster care for children with complex medical needs; residential school programs; physical and speech therapy; working with natural parents for family reunification; and coaching and counseling foster parents.

The staff members interviewed reported a total of 561 children with developmental disabilities were being served by these agencies. All of them maintained waiting lists, with a total of 98 children waiting for services from all agencies except Catholic Social Services. (Additional interviews would need to be conducted to obtain the number of children on that agency's waiting lists, as the lists are maintained by individual programs within that agency).

When asked to rank the most important issues with which the Department of Children and Family Services would need to deal in order to improve out-of-home services for children with developmental disabilities, the following responses were obtained (from most to least important):

- **Diagnosis and evaluation** -- it was reported that children were not always

recognized by DCFS field staff as having developmental disabilities. Case workers also were reported as sometimes mislabelling children as developmentally disabled because case workers feel the natural home was depriving the children of needed stimulation. By labelling the children as disabled, case workers make children eligible for more early intervention and other services.

- **Interagency relationships between the Department of Children and Family Services and the Department of Mental Health and Developmental Disabilities** -- problems in interagency coordination were mentioned by all four persons interviewed.

    - These problems affect the development of services for children -- for example, the foster care supervisor at Lutheran Social Services mentioned that she routinely turns away children who could be funded by the Department of Mental Health and Developmental Disabilities because that department has a cap on funding foster care. Thus, parents who want to voluntarily place children out of their home are unable to do so. Whereas, wards of Children and Family Services, removed from their natural homes by the legal system due to abuse or neglect, never have difficulty in obtaining funding for foster care.

    - When children "age out" of services funded by the Department of Children and Family Services, they often have nowhere to go and are inappropriately held in childrens' facilities. This continued inappropriate placement is a direct result of the lack of alternative placements funded by the Department of Mental Health and Developmental Disabilities.

- **Licensing standards and their impact on reimbursement rates for facilities serving children** -- according to two persons, the Department of Children and Family Services did not distinguish between the needs of children who were mildly impaired from the needs of children with severe or multiple impairments. Unlike the Department of Public Aid, the Department of Children and Family Services does not provide additional reimbursement, through the per diem rate paid to these facilities, to meet the needs of children who have more severe medical, behavioral or developmental needs. This directly affects the ability of service providers to meet the needs of the children and youth for whom they care.

- **Providing community supports and services to both natural and foster parents** -- this was identified as a problem, both in terms of preventing out-of-home placements and in terms of the philosophy of permanency planning. The informants felt that more needs to be done in terms of prevention and that more creative means of supporting foster care placements (such as support for foster families' transportation needs, and offering respite care for foster families) would promote more stable homes or foster placements for children and youth.

- **Reimbursement for providing foster or residential care** -- increasing the reimbursement rate was ranked fifth, as an issue with which they believed DCFS should deal. Little additional information was obtained regarding why the informants felt increased reimbursement was necessary, other than the problems mentioned above in meeting the individual needs of children and youth.

Other issues identified were the interface of the local educational systems with the Departments of Children and Family Services and Mental Health and Developmental Disabilities; and the criteria used for funding out-of-district educational services and resulting difficulties in obtaining funding of related services for occupational therapy, physical therapy and speech therapy.

When asked simply to identify the "biggest problem facing the Department of Children and Family Services in trying to improve services and supports for children with disabilities," the four persons interviewed all mentioned the need for DCFS to assure better training of its staff. They said that DCFS staff need training in recognizing the needs of children with developmental disabilities; that these children were not being identified soon enough to benefit from intensive service delivery; and that DCFS staff showed little expertise in dealing with the families of persons with developmental disabilities. Also mentioned were a lack of funding and the slow-moving licensing process for foster care. Lutheran Social Services reported that even though a foster placement for a child with a developmental disability was arranged and the foster parents were trained ready to accept a child, they wait a long time (sometimes up to a year) before the Department licenses the home.

The four persons interviewed rated the Department of Children and Family Services as doing a poor job in service facilitation. When asked what the Department could do to improve service facilitation, they again mentioned DCFS' lack of expertise in dealing with children with developmental disabilities. In addition, they cited the need for smaller case loads and clearer lines of authority for the approval of needed services. Developing more resources in local communities also was cited as a need. These resources should include transportation mechanisms for children in wheelchairs; respite care for foster parents; family support to natural and foster parents; short-term residential treatment; and adult residential services. One person stressed the need for case workers to obtain valid assessment information to better identify the services children need upon intake.

The persons interviewed also identified issues that Children and Family Services needs to resolve to improve Illinois' system of providing out-of-home care to children. These issues included:

- developing more local resources (as described above);
- linking DCFS and DMHDD service facilitation/case coordination systems to benefit children and families;
- identifying parents with developmental disabilities to provide parenting support (and thus prevent out-of-home placement);

- resolving morale problems within the Department (especially in Cook County, where many case workers feel that they've been scapegoated for the Department's systemic problems);

- funding of residential services for children with developmental disabilities, which are underfunded in comparison to per diems paid for facilities offering mental health services to children;

- changing the name of the licensing standards from "child care institution" to "child care facility;" and

- streamlining approval for needed surgical interventions (as many interventions which improve functional ability are misclassified as "cosmetic," and thus, are not funded).

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Appendix A

Annotated Bibliography

- Larson, S. & Lakin, C. (1991) Parent attitudes about residential placement before and after deinstitutionalization. *Journal of the Association for Persons with Severe Handicaps, 16(1)*, 25-38.

  This article reports findings that support the trend toward deinstitutionalization, including the literature review that cites Meyer's finding that younger parents were more likely to prefer community placement. Larson and Lakin have a useful table which summarizes parent attitudes concerning the benefits (positive outcomes) of community placement (after deinstitutionalization); articles citing improvements in adaptive behavior are listed here, too.

- Taylor, R. (1981) *The kid business: How it exploits the children it should help.* Boston: Houghton Mifflin Company.

  Taylor describes the result of his investigative reporting on residential child care issues. He says that

  > in every facility I found children who were simply lost -- abandoned and cast adrift in a foster-care system that was indifferent at best, brutal at worst. These children were bounced through foster homes, placed in and taken out of group homes, private and public institutions, in the most arbitrary, capricious ways; I had stumbled into a situation so bizarre that it was overwhelming. At times I could make no sense of what I was seeing. It was as though I had followed Alice through the looking-glass into the backward-living world and was lost in the dark forest inhabited by the Jabberwock:
  >
  > *Beware the Jabberwock, my son!*
  > *The jaws that bite, the claws that catch!*
  > *Beware the Jubjub bird, and shun*
  > *The frumious Bandersnatch!*
  >
  > In the bureaucratic house of mirrors I found deaf children who were being slapped about the head because they couldn't hear and obey orders; helpless, retarded children who were placed in 'homes' for seriously disturbed, aggressive delinquents just out of kid prisons; normal, health youngsters who were placed in private institutions for the retarded, where they were drugged, beaten, and

forced into manual labor; homeless children who were locked away in jail cells or committed to psychiatric hospital wards because there was nowhere else to put the. All this was done as a matter of public policy, but I could find no accountability in any agency or institution.

He reviews, in detail, the stated goals of the federal child welfare system, the practices of juvenile courts, financial disincentives that made it easier to fund out-of-home placement than to provide the family-support services needed to keep children at home, and studies by public and private investigators (the New York City comptroller, the National Commission on Children in Need of Parents, the New Orleans Parish district attorney's office, the city of Chicago's legal aid agency -- attorney Patrick Murphy, the California Children's Lobby, the General Accounting Office, the California Department of Health, CBS' *60 Minutes* and others).

Of particular interest is a report by an Illinois Task Force titled, *An Illinois Tragedy*. Taylor cites a statement by the report's principal author, Professor Patrick Keenan of DePaul University, that said the bureaucracy of the Department of Children and Family Services, "was designed to prevent investigators from finding anyone who was responsible or accountable (for deaths and abuses that occurred in out-of-home placements in the state of Texas between 1963 and 1973). The lines of communication between social workers in the field and their supervisors wound their way so tortuously through one layer of the bureaucracy to the next that no decisions could be made and responsibility for inaction could not be traced." The *Gary W.* case was closely related to these events, as it concerned children placed out-of-state from Louisiana in Texas institutions. *An Illinois Tragedy* was quoted extensively in the case complaint. In 1976, Judge Alvin Rubin ruled that the class of Louisiana children had to be returned to Louisiana and that appropriate placements had to be made near the childrens' home communities. Furthermore, he established the rights of these children to the least restrictive treatment, to individualized treatment, to due process prior to placement, to humane treatment and care and to protection from cruel and unusual punishment. Importantly, the judge also ordered that Louisiana had to pay private institutions within the state at least as much as it paid out-of-state facilities.

In another expose of conditions inside a private, for-profit Illinois facility, as reported in the Chicago *Sun-Times* in 1977, former employees of the Windgate Home for 52 children with mental retardation reported abuse of the children, leading the Department of Children and Family Services to initiate hearings to revoke the license for the facility. Most of Windgate's children had been placed by DMHDD, some by DCFS, and each of them received a State Board of Education grant for residential schooling. The hearing officer concluded that the facility's "staff had used hot sauce on children's tongues, had finger-flicked their noses and ears painfully, had given them cold-water showers, restrained them in their beds, tied them hand and foot to potty chairs, all in the name of behavior modification. The hearing officer found the education and recreation classes inadequate and the staff not well trained . . . A year's probation was recommended."

A task force formed to investigate the circumstances surrounding Windgate's abuse of children concluded:

> the systems of service delivery of the three agencies (DMH-DD, DCFS, and ISBE) lacked the communication, coordination, cooperation, and resources to adequately discharge their mandated responsibilities. Further, monitoring guidelines and license standards are insufficient or do not exist at all for community-based residential facilities and therefore the process of measuring the quality of services is greatly impeded.

Taylor ends his book by comparing his investigations of foster care in the United States with the system established in Sweden. Sweden pays parents to keep their children at home. Karl Grunewald, director of the National Board of Health and Welfare's Department for the Care of Mentally Retarded, explained to Taylor, "the national and county funds are allowed up to the full cost of what institutional care would have been, which allows parents enough money to bring in the kind of help they need. There is no practical limit on how much the cost will run. We don't even discuss maximum payments." In addition, when the author told representatives of the Swedish national children's ombudsman of conditions in some American child care facilities, he told the author, "in Sweden (this) would not be possible . . . If there are four children or more, there would be a medical doctor -- a psychiatrist -- and a staff of trained people available. There would be too many trained professional people involved and they would not allow such things to happen." Group homes for children with mental retardation were inspected by experts like Grunewald, who said, "there are constant contacts, daily, with outsiders, so any child abuse is quickly picked up." The author describes the difference between the two countries, as follows: "In Sweden, there is a national mandate, a national policy. The people of Sweden have decided that local governments *will* provide health care, preschool programs, rent subsidies, social and rehabilitative services for children and their families. In the United States, the local governments decide whether or not they will provide public assistance in any form, and, if so, how much."

- Zirpoli, T. & Wieck, C. (1989) Economic and political factors affecting deinstitutionalization: one state's analysis. *The Journal of Special Education, 23(2)*, 201-211.

Again, describes trends away from using institutional care for children with developmental disabilities. Economic and political alternatives are presented in the article, so that the impact of institutional closure can be ameliorated, and institutional closure can be accelerated. These alternative strategies and uses included:

1) Presenting the enormous costs of institutional care (90% of which involves personnel costs) to politicians and their constituents.

2) Decreasing the unemployment impacts of institutional closure through providing additional training to institutional staff (who already have many of the skills necessary to work with individuals with disabilities) so that they may qualify for new community-based positions.

3) Alternative use of state institutional facilities, including conversion to use for other public uses (to prison space, alcohol and chemical dependency treatment facilities, state and local agency administrative office space, public health services, and geriatric facilities) and private uses (demolition of institutional buildings and sale of the land, and use of vacant buildings by churches, industry and other commercial interests).

The following annotated citations come from the Association for the Care of Children's Health (3615 Wisconsin Ave., N.W., Washington, D.C. 20016, (202) 244-1801), 1984 Edition of *Home care for children: an annotated bibliography.*

- Glick, R., Guyer, B., Burr, B. & Gorback, I. (1983) Pediatric nursing homes: Implications of the Massachusetts' experience for residential care for multiply-handicapped children. *New England journal of medicine, (309)11, 640-655.*

  This study describes the effects of pediatric nursing homes developed in 1971 as a response to the crisis created by deinstitutionalizing severely handicapped children. A low turnover rate resulted in the number of beds quickly becoming inadequate. Further, inconsistent standards, fragmented care, lack of long term planning, and inadequate financing resulted in less than optimal educational and rehabilitative services. This article provides a glance into what can happen when major changes in delivery of services occur too quickly, and gives recommendations for changes in the future.

- Winsberg, B., Bialer, I., Kupietz, S., Botti, E. & Balka, E. (1980) Home vs. hospital care of children with behavior disorders. *Archives of general psychiatry, (37), 413-418.*

  This article reports a research investigation which compared treatment outcomes of community and hospital care for children with behavior disorders. Forty-nine children from working class backgrounds, but medically indigent, were studied. The children ranged in age from five to thirteen years old and thirty-four of the children came from single parent families. Results demonstrated that community care was effective with regard to behavioral control, and that both treatment groups were comparable in educational achievement, parent role function, family adjustment and parental satisfaction with treatment.

Appendix B

***Children's Facilities Licensed by the Department of Public Health** (as of 6-1-92)*

Except as noted, all licenses are unrestricted.

Name of Facility	Number of Licensed Beds
Augustana Center for DD Children 7464 N. Sheridan Rd. Chicago, Il. 60626	150
Champaign Children's Home 109 Kenwood Rd. Champaign, Il. 61820	87
Children's Habilitation Center 121 W. 154th St. Harvey, Il. 60426	118
Deicke Center - Marklund Children's Home 27W751 Shady Way Winfield, Il. 60198	42
The Elaine Boyd Creche 267 E. Lake St. Bloomingdale, Il. 60108	109
Exceptional Cr. & Training Center 2601 Woodlawn Rd. Sterling, Il. 61081	79
Grove School Residential Center 40 East Old Mill Rd. Lake Forest, Il. 60045	48
Little Angels Nursing Home 1435 Summitt Street Elgin, Il. 60120	50
Marklund Children's Home 164 S. Prairie Ave. Bloomingdale, Il. 60108	98

Miseracordia Home — 110
2916 W. 47th St.
Chicago, Il. 60632

Nursing Center of Canton — 32
1675 E. Ash St.
Canton, Il. 61520

St. Luke's Health Care Center — 50
Rural Route 3
Beardstown, Il. 62618

Styrest Nursing Home — 108
120 N. Tower Rd.
Carbondale, Il. 62901
(License status: conditional -- while listed by DPH as a licensed facility, Southern Illinois Case Coordination Services, Inc. relocated all children served by Styrest after it was determined that children had been repeatedly abused by facility staff).

Walter Lawson Children's Home — 93
1820 Walter Lawson Dr.
Loves Park, Il. 61111

Appendix C

Deficiencies Cited in Recent Surveys of Illinois ICFs-MR for persons under 22 years of age

The deficiencies presented in this Appendix were cited by Illinois Department of Public Health surveyors in survey reports for facilities serving children and youth under 22 years of age. Although deficiencies for individual facilities are not identified, it should be noted some of the facilities had lengthy survey reports, detailing many violations of the federal ICF-MR and/or state ICF/DD regulations that threatened the certification of some facilities; whereas, in others there were very few or no violations (such as Miseracordia and the Walter Lawson Children's Home). The Department of Public Health accepted all Plans of Correction from facilities, thus preserving the ability of the state to claim federal matching dollars for the placement of children and youth in the facilities. Even in facilities that were essentially free of deficiencies, concerns were expressed by surveyors, due to the practice in these facilities of placing more than 4 children in a room. Waivers of the four-person limit were requested by these facilities because of what the facilities assert is the need for continuous medical monitoring of the children. The presentation of this information is not intended as an indictment of individual facilities, but of the system that sustains them and of the attitudes congregate care tends to promote in the staff of such facilities. Please note that the statements made by the surveyors are excerpts from more comprehensive survey reports. The plans of correction written in response to these statements involve the facilities' responses to the federal and/or state requirements and usually provide little additional information about the observations -- thus, the facilities plans for complying with the regulations are not included in this Appendix.

The observations of the Public Health surveyors are organized in the following pages by the type of violation that was cited. In order to protect the confidentiality of the children and youth and individual staff members involved, the DPH surveyors use the convention of identifying them by a code (e.g., R# or E#); "R" is the abbreviation for "resident" and "E" is the abbreviation for "employee." All observations and findings of the same survey date are for the same facility -- observations about single individuals can be found by looking across all categories for their individual code numbers, according to common survey dates. While other abbreviations were used in the statements written by the surveyors, the proper words were substituted for the abbreviations (e.g., "q" = "every," etc.) in the transcription below. Also, People First language was substituted for the terms such as "client." Other than these substitutions, and minor editorial changes made for the sake of clarity, the observations are presented verbatim.

Human Rights

Date of survey	Observations/Findings
9-6-91	Staff working with R39 use a method of blocking her wheelchair to prevent her from moving from place to place that is not incorporated into

her Individualized Program Plan. **R39's wheelchair wheels were tied with a rope-like material to prevent her from moving her chair away from her table**, on 9-4-91, at 6:05 p.m.

10-23-91* On 10-16-91, during the supper meal time, **staff referred to R50 as "crunch a munch"** as they entered the dining room and asked about him. Example: "How is crunch a munch tonight?" "Did crunch a munch behave tonight?" **This reference is to his behavior of biting himself and others around him.**

---

*follow-up to survey of 9-6-91

3-26-92 The facility must inform each person living in it, parent (if the person is a minor), or legal guardian of the person's rights and the rules of the facility. This standard is not met as evidenced by: a clinic appointment agreement that is signed by parents of residents who are minors. This agreement, signed upon admission, does not inform parents of what the facility will do if parents fail to adhere to the clinic appointment agreement. The agreement only states parents are responsible to take their children to clinic/doctor's appointments. **Failure to keep clinic appointments has resulted in parents being reported to the Hotline for the Department of Children and Family Services for medical abuse since November, 1990.**

3-26-92 The facility must inform each person living in it, parent (if the person is a minor), or legal guardian of the person's medical condition. This standard is not met as evidenced by: parents who came to the facility for a Parent Group meeting found their child to have a bruise on her leg. When parents came to visit, they found the children on mats in the Activity Room unattended. During interview with social worker, it was revealed the staff reported this resident was bruised by another person living in the facility. The date of this incident was 2-5-92. The incident report of 2-5-92 addressed scratches on face. The date of typewritten letter informing the parents was 2-13-92. There was no information in the letter telling the parents of the bruise on the leg. The date of the Parent Group meeting was 2-29-92. There is another incident report of 2-21-92 regarding abrasion on foot, "cause unknown." The parents were not informed of this. The facility incident/accident reporting system entails notifying the Illinois Department of Public Health, police, physician and family. R16's family member stated, during a group interview, that they were notified of an injury to R16's face. However, upon visits to facility, **it has been found that 2 out of 3 injuries to R16 were not reported to family.**

3-26-92

Individual residents' Supplemental Security Income monies are used to purchase specific supplies, adaptive equipment, toys, utensils, televisions, stereos, radios, etc. These properties are, in many instances, used for the general population of the facility. Examples:

- On 3-25-92, at 9:20 a.m., surveyor went into Classroom 117. A radio was playing. Surveyor asked a teacher's aide, to whom does that radio belong? Surveyor was told it belongs to R15. R15 was not in the room nor was any of the other persons living in the facility. The radio was being used by the staff.
- On tour of Classroom 107, surveyor observed a positioning wedge with the first name of a person on it. Surveyor asked teacher's aide if that person was in this classroom. "No," stated the teacher's aide, "I borrowed it. But I bring it back each day to that person's classroom"
- R4 purchased and paid for a mug with a drinking spout . . . it was reported by staff that individual mugs are not labelled generally. Each floor is sent the adaptive utensils needed. The Qualified Mental Retardation Professional stated R4 is not using a mug with a spout. In addition, the mug purchased by R4 is stored unlabelled in Dietary and is used by the general population.

The use of individual properties purchased through SSI monies is widespread.

3-26-92

Individual possessions are not protected from loss, due to theft or destruction by others as noted by inventories made by Qualified Mental Retardation Professionals for the persons on their caseloads. **"Not found" is listed on the inventories as the condition of many beanbag chairs, radios, adaptive toys, and balance chair adaptive equipment.** Examples:

- R7 purchased, through SSI monies, a beanbag chair for $103.51, a balance chair at $214.90, and therapy equipment valued at $300.00. All missing. All "never seen" by R7's QMRP, as reported to surveyor on 3-25-92.
- R2's SSI monies were used to purchase a full body sling on 10-17-91 for $110.50. When the surveyor inquired about the whereabouts of this body sling, R2's Qualified Mental Retardation Professional did not know where it was. The Assistant Director of Education did not remember ever seeing it, nor did the registered nurse on the 3rd floor, nor did another aide. The Physical Therapy person in the morning of 3-25-92 did not remember ever seeing it either. An hour after the inquiry was made, the Qualified Mental Retardation Professional for R2 brought a brand new black body sling to the surveyor. "We found it in the backpack for R2." **It was highly questionable whether this piece of equipment had ever been used.** It was perfectly folded, unwrinkled and there was no evidence of it ever being laundered -- the tag was flat and unwrinkled and the

stiffness from not being used was still apparent five months after R2's monies were used to purchase this piece of equipment.

4-16-92

On 4-15-92, **R12 was observed to be naked to the waist from 8:30 a.m. through 8:50 a.m. without staff intervention**. R12 was sitting in her crib rocking. She is a 20 year-old, well-developed female. At 8:42 a.m., R9, a man who lives in the facility, was wheeled through R12's bedroom in direct full view of R12. **No privacy was ensured for R12.** On 4-15-92, at 8:55 a.m., R12 was being bathed in a shower chair. E8, a male staff person, entered the room without knocking on the door. R12 was fully naked -- **staff did not ensure privacy by knocking before entering**.

4-16-92

On 4-15-92, at 8:05 a.m., R13, who is a woman who lives in the facility, was observed to be **wearing thermal male long-legged underwear**. She was **also wearing a T-shirt with R9's name on the outside chest pocket and socks labelled with R14's name**.

4-16-92

Lack of respect, dignity and positive regard for persons living in the facility were observed in the following examples:

- On 4-15-92, at 8:15 a.m., in the bathing room of Room 9A, R13 was being dried with a towel while lying on a padded counter whining and crying when a staff entered the room and said, "What's the matter?" to the staff attending R13. Staff replied, "She's just fussy." Whereupon the other staff person said to R13, "Oh, you brat," and left the room.
- On 4-14-92, at 6 p.m., in the north hall team room, surveyor observed the Assistant Director of Nursing state to R10 who was crying, as habilitation technician was attempting to spoon feed R10's dinner meal, "If you eat 100% of your meal, I'll let you call your mother and talk to her." R10 continued to cry with even increased intensity.

Assessment of Needs

Date of survey	Observations/Findings
3-5-92	Review of R4 through R6's record revealed no updated speech assessment (none since 1990). Interview of E1 revealed audiology assessments are not done unless someone recommends it and **there has been no speech therapist for almost one year**.
3-26-92	R1 was assessed in January, 1992, as exhibiting the following maladaptive behaviors -- hitting self, hand mouthing and pants digging. Referral was made to Behavior Management Department in February, 1992. Recommendation was made to collect baseline data on hitting self and pants digging. A note from the behavior management person was noted

in R1's record for the recreation person to start collecting data. The collection sheets were noted in the person's record. These sheets were date 3-10 through 3-31-92. No data had been collected as of 3-24-92. On 3-24, surveyor asked why data had not been collected. **E2 replied she didn't understand what the behavior person wanted. Because of this she could not let the workers know what to do. E2 stated she had not had a chance to talk with the behavior person because she works different hours.**

3-26-92

R2 has made no progress in communication program, which is to sign "more," "eat," and "drink." R2 has been assessed as not expressing wants or needs for diaper change, food, etc. R2 had no communication device when observed by surveyor on 3-25 and 3-26. **Speech and language evaluation/update of expressive language does not recommend a language board/alternative communication devices or objectives for this person.**

3-26-92

R4 was readmitted to the facility after having a spinal fusion. Hospital transfer sheet, dated 2-18-92, documents "range of motion lower extremities if able." Doctor's order sheet 2-92 and 3-92 had order for range of motion to lower extremities. **No evidence of physical therapy assessment and no documentation of treatment. Last physical therapy assessment was done in 1990.**

Staff Training and Supervision

Date of survey

Observations/Findings

9-6-91

On 9-3-91, during the 3 p.m. to 11 p.m. shift, 13 out of 21 Certified Nursing Assistants (CNAs) were agency CNAs. Interview of E1 and E2 revealed **there is no orientation of temporary agency personnel to the facility or the persons living in it.** E19 (a nurse) stated on 9-3-91, during the 5 p.m. medication pass, that she was in the facility for the 3rd time. In response to a question regarding orientation to the facility, E19 stated she was with another nurse, but on the second day, facility was short-staffed and E19 had to be on her own. September 3, 1991 was her third day in the facility, but **she did not know all the persons with whom she was assigned to work and had to rely on E20 to identify R64 prior to medication administration** . . . Interview of E9, E10, E11, E12, E13, and E14 on 9-5-91 revealed that agency CNAs are not being oriented to the facility or residents. **CNAs could not discuss current goals, or any special programs required in resident habilitation plans or care.**

3-26-92

R4, diagnosed as having profound mental retardation, was observed being fed lunch, on 3-23-92. Six bibs were placed around R4's chest and shoulder area. **R4 had great difficulty swallowing and was noted to cough and choke after receiving liquid Ensure.** E7 held cup and bibs around mouth while giving Ensure. Approximately 6 ounces were attempted to be given before E7 stopped. The Ensure being given at this time was the 10 a.m. supplement. The person drinking the Ensure was to receive additional Ensure at lunch. **No spout cup or wrist support for spoon was used as ordered on physician's order sheet.** Surveyor spoke with E10. E10 told surveyor **R4 had weight loss and problems with eating** and E10 recommended pureed diet on 2-28-92.

3-26-92

Thickener is to be added to thin liquids, when there is a doctor's order, to prevent aspiration and/or choking. R7 has a doctor's order for thickened liquids. On 3-24, R7 was sent a 3 p juice in carton. This is thin and thickener was not added in kitchen. **R7 received thin liquids by floor staff.** R7 also has an order for "food fortified with supplement during preparation." Dietitian stated that this meant that margarine was to be added to foods in kitchen during preparation. Surveyor observed supper meal 3-25-92. **Kitchen staff questioned regarding "food fortified during prep" on diet card and E11 not aware of meaning. E12 cook and server not aware of policy and procedure.** No residents received this 3-25-92 supper meal. **No dietary manager or supervisor present to monitor diet staff.**

4-16-92

On 4-15-92, at 11:45 a.m., staff was observed to brush R23's teeth in the following manner: **staff held R23's head with her left arm in what appeared to be a "headlock"-type of hold.** Staff's left arm encircled R23's head with left hand securing chin, while vigorously scrubbing teeth with toothbrush. R23 responded by struggling with arms extended and grabbing at staff with hand while attempting to move head. No verbal prompting was given to R23 prior to initiation of the maneuver. R23 calmed and smiled when procedure was complete and head was released. Staff commented that at least R23 "didn't hold a grudge." R23's medical record reveals R23 is extremely sensitive to tactile stimulation of the head.

4-16-92

Staff was observed pouring R25's carton of Great Shake directly into his mouth. **Staff did not attempt to use a glass.** R25 consumed only 80% of his meal due to the fact that staff did not attempt to open or offer R25 his chocolate milk.

Opportunities for Choice and Self-management

Date of survey	Observations/Findings
9-6-91	R45 was observed, on 9-4-91, to be crying and yelling loudly as she was sitting in her wheelchair in her room at 4:35 p.m. When E23 was asked by surveyor why R45 was upset, E23 stated R45 loves music and was in the music room (next to her own room) but had to be taken out and brought to her room for a bath because she was drooling excessively and E23 didn't want R45 to go to dinner dirty. **R45 was not given a choice as to whether she wanted her bath at that time or to enjoy music.**
4-16-92	At the noon meal (11:45 a.m.) on 4-15-92, R17 was served lasagna. Staff stated to R17: **"I know you don't like it but you have to eat this."** E7 stated: "In the past I was told by the dietary worker that it could not be changed, unless he was allergic to the food." R17 ate approximately 20% of this meal.

Active Treatment

Date of survey	Observations/Findings
9-6-91	• R73 was observed in his room, on 9-4-91, at 8:13 a.m. slapping the side of his face. **There were no interventions to stop this behavior.** • R5 was observed sitting in his wheelchair in the hallway banging his head on the wall as he waited for the bus. **There were no interventions to stop this behavior.** Occurred on 9-4-91, at 8:20 a.m.
9-6-91	• R57 was **observed on 9-3-91**, at 5:05 p.m., in the high school classroom. R57 was wearing gray sweatpants which were wet from urine. • R57 was again observed at 6:05 p.m. in first floor hallway. Pants still wet from urine. • R57 was again observed in 2nd floor hallway at 6:20 p.m. Pants still wet from urine. • R57 was then observed at 6:35 p.m. He was placed in an empty bathtub to have clothing changed before being bathed. • R57 was **observed on 9-4-91** at 4:17 p.m. in 2nd floor hallway. He was wearing yellow sweatpants which were wet from urine. • Observed again at 5:15 p.m. in high school classroom. Pants still wet from urine. • Observed again at 6:50 p.m. in bedroom. R57's pants still wet from urine.
9-6-91	R50 was observed, on 9-4-91, at 7:25 p.m., in 2nd floor middle dining

room. R50 had been chewing on a sock. Certified Nursing Assistant E6 stated she gave this person a sock to chew on because she will bite her own hands. **Aide was not aware of any program to intervene in this behavior.** During record review, it was noted that the person's Individualized Program Plan does not address hand biting. R50 has **no program developed to address this behavior or meet needs.**

9-6-91

R12 currently has an eating program to self-feed. Staff is to state, "Pick up your spoon and eat." If he does not, then staff is to repeat above statement. If he does pick up spoon then a tape is to be played on a tape recorder. R12 was observed at evening meal on 9-3-91 from 5:30 p.m. to 6 p.m. **R12 was observed to eat meal with his hands -- no staff intervention was observed. No encouragement to utilize spoon was noted. R12's food (sausage) was not cut up and at 6 p.m., half of his sausage and bread was noted under his wheelchair.**

9-6-91

R28 receives a "prn" (as needed) order for 500 milligrams of chloral hydrate prior to getting a haircut. Lack of documentation in his record suggests **the team has not tried positive behavioral approaches prior to the use of medication to get him to cooperate in having his hair cut.**

3-5-92

On 3/4/92, R8 had a slight elevated temperature and so was not taken to class for that day -- R8 did not have to remain in his room, as temperature was 99.7 degrees (rectal) at 8 a.m., this day. At 9:20 a.m. direct care staff placed R8 in an adaptive wheelchair in hallway near nurse's station. R8 remained there until 11:15 a.m., a period of about 2 hours. **At no time during this 2 hour period did staff interact with this person either verbally or physically.**

3-5-92

On 3/3/92, from 5:04 p.m. until 5:55 p.m., **16 persons were lined up in their wheelchairs down the hall with their backs to a wall and facing the other side of the hall displaying numerous self-stimulatory behaviors with no staff intervention.** Per interview with staff, these people were waiting for dinner.

3-5-92

R12 attends the Illinois School for the Visually Impaired during the day. R12 does not have a continuous active treatment program. There are no IPP structured objectives established or implemented at the individual's living unit. Direct observation of R12 on 3/3/92, from 4:15 p.m. until 4:32 p.m., revealed R12 curled up in a chair with her head resting on the wooden arm -- sleeping.

- At 4:32 p.m. R12 was awakened by staff and a bib applied to her and staff left and R12 resumed the same position.
- At 4:57 p.m. **staff awoke R12 again and fed R12 the entire meal**

even though R12's IPP identified that self-feeding was a strength. R12 was fed from dishes on a plastic tray and at the nurses "desk" counter.
- From 5:25 p.m. (when meal finished) until 5:50 p.m. R12 remained at the "desk," curled up, sleeping in the same chair.
- At 5:50 p.m., R12 was taken to the recreation room where she was placed in the same type of chair, resumed the same position and slept until 6:50 p.m. when surveyor left.

3-26-92

R13, who is not in a day program at the present time, and per documentation from E9 on 11-27-91, R13 was not accepted at VCNA "because of lack of toilet training." **R13 is not in a toilet training program at this time**, per E3.

3-26-92

R2 receives medication to control his face-hitting behavior. **R2 has had no reduction in medication during the past year, even though R2 has met the behavioral goal on his residential unit, showing low frequency behavior in the classroom (data collection in recreation has not been recorded consistently), and does not exhibit self-injurious behavior, according to the psychologist, but, rather, has stereotypical behavior which interferes with his program**. R2 had an Individual Program Plan staffing, on 3-18-92, and surveyor's discussion with QMRP and psychologist, on 3-25-92, regarding R2, indicated no medication reduction was recommended by the team.

4-16-92

On 4-15-92, from 6:30 a.m. thru 8:45 a.m., **R12 was sleeping and/or awake in a crib without a pillow and sheet covering her mattress**. Staff told surveyor that R12 chewed the sheet when she became upset and that was probably why no sheet was on her bed.

4-16-92

R12 was observed to be rocking in her bed hard enough to rock the metal crib, which made a loud noise of metal against metal, and she was humming loudly. This behavior occurred from 8:00 a.m. to 8:25 a.m., on 4-15-92. **No staff intervention was observed**. Verbal prompts from a staff person, who was bathing another person in another room, were heard. The verbal prompts were, "R12 -- stop!" R12 would immediately stop, but would resume the maladaptive behavior within a few seconds. At 8:25 a.m., R12 laid down on the bare mattress, closed her eyes and put her hand in her mouth. At 8:30 a.m. R12 awoke and resumed previous behavior described -- **no staff intervention was implemented. Three staff walked in and out of R12's bedroom without intervening.** On 4-15-92 at 11:40 a.m. in the secondary classroom R12 was observed for three minutes with her foot up to her mouth chewing on the shoestring. **Three Certified Nursing Assistants and one nurse were in the room with no staff intervention or redirection**. A staff person was

heard to say, "I won't be able to feed R17 if I have to redirect R12 all the time."

4-16-92

R16 is on a program to participate in a community outing monthly. The data sheet for R16's program is blank. **The teacher stated to surveyor that R16 did not complete his community integration program because the teacher did not have a driver's license and couldn't drive the van.**

5-7-92

R2 is a 6 month old infant with a borderline functional level **who had met his goals and did not have program revision or consideration for new goals for four months.** These out-of-date goals are: to respond to sounds and objects presented; to maintain grasp in caregivers finger; and 6 seconds of supported sitting. This baby has achieved these goals at 100% for four months. Surveyor observed R2, at approximately 10 a.m., in his walker, moving about his classroom. **The Qualified Mental Retardation Professional said that R2 was continuing to progress "better than expected."**

Food and Nutrition

Date of survey	Observations/Findings
9-6-91	R21 was observed on 9-3-91 at dinner. • At 5:20 p.m., she began to tantrum, as evidenced by loud screaming, and throwing herself back in her wheelchair. **Surveyor asked, "Is she hungry?" Staff replied, "I don't know."** Staff tried to engage her with a ball, by looking in a mirror, and by holding a place mat, with no success in reducing the behavior. • At 5:25 p.m., staff removed her from room in order to change her diaper and give her some water. • At 5:40 p.m., she was brought back to dining area screaming louder than previously observed. A registered nurse came into area and began singing to her and stroking her arm. **At this point, blood was noticed on her lip and chin.** R21 quieted to the singing and quiet talking, however, • at 5:45 p.m., R21 started tantrumming again. At this time, staff removed her from her wheelchair, and wrapped her in a blanket. Screaming continued. • At 5:55 p.m., R21 was placed back in her wheel chair and a staff member attempted to feed her. R21 then proceeded to quiet down. • **R21 remained quiet and unengaged in the room until 7:00 p.m., when she was placed in her room. Documentation by staff of this incident read, "R21 likes to be fed first."**

3-26-92	**R18 was falling asleep, while being fed, and his head was falling backwards, causing R18 to cough and choke and cry. R18 has a feeding plan to keep his head upright and neck in proper alignment to facilitate swallowing.** E15 stated R18 is "tired" and "keeps falling asleep."
3-26-92	• **At 2:00 p.m., 13 people were observed waiting to be fed and changed and were sleeping and/or crying.** • **At 2:25 p.m., 5 people were still eating lunch . . . and 3 were left to be fed.** • **All lunch was finished about 2:45 p.m.**
5-13-92*	R4 is to receive 240 cubic centimeters of Ensure Plus, every 4 hours, by a nasal-gastric tube, and is to have the head of the bed elevated 30 degrees or more during feeding per physician's orders of 5-1-92. On 5-12-92, at 4:50 p.m. in Room 320, R4 was observed during meal time lying in bed with no head elevation and the Ensure Plus was not infusing. Staff with R4 did not know why the Ensure was not infusing and left the room to get the nurse. The nurse entered the room shortly thereafter and proceeded to correctly position R4 and told staff person to keep R4's "head up" when Ensure is infusing. **Since R4 requires a feeding every 4 hours, all staff should be aware of R4's positioning requirements.**

*follow-up to 3-26-92 survey

Health Services

Date of survey	Observations/Findings
9-6-91	R16's seizure record, at day training, indicates R16 had seizures at the day training program, on 8-13 and 8-20-91, with seizure on 8-13 lasting 4 minutes and 30 seconds. **Seizure chart on medical record at facility does not indicate these seizures occurred. Physician's progress notes on record at facility states R16 is "seizure free."** Record at facility states R16 had a seizure at day training program on 9-4 lasting 4 minutes, however this was not recorded on day training program's seizure record . . . **R16's seizure record indicates R16 has had seizures frequently in June, July and August, both at day training program and in facility, even thought doctor's progress notes of 8-11-91 state, "seizure free." R16's blood level for Tegretol and Phenobarbital done in 2-91 and 8-91 were not within normal (therapeutic) levels.**
9-6-91	R90's suction collection bottle contained approximately 250 cubic centimeters of cloudy fluid when observed at 7:45 p.m. on 9-3-91 and on

9-4-91 at 9:25 a.m. There was no record R90 required suctioning during this time frame. Interview with E18 on 9-4-91 revealed the collection bottles are to be emptied and cleaned after each shift. **E18 stated she was unaware that R89 or R90 required suctioning during the night and stated "The night shift forgot to empty the containers."**

10-23-91*

R79 was lying in her crib with her head in the corner of her crib where her left side of forehead and upper portion of head had reddened skin. At 6:05 p.m., surveyor asked the Qualified Mental Retardation Professional (QMRP) if R79 could be repositioned. **She stated she could not do it because she was feeding R64. Surveyor then asked QMRP if she knew where the call lights were located -- she said, "no." The child was repositioned at 6:28 when a Certified Nursing Assistant came into room.**

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*follow-up to survey of 9-6-91

3-26-92

R4 (date of birth 11-06-70), diagnosed as having profound mental retardation and cerebral palsy, had surgery in January, 1992, for scoliosis repair; and posterior and anterior spinal fusion. R4 returned to the facility on 2-17-92. Transfer form states "open sore at the back of R4's head was more of a pressure sore than a cyst . . . The open sore has healed. Suggest position change often . . . while in bed to prevent him from getting too much pressure on one part of head and body . . . May be in sitting position in his wheel chair with his brace only and with adequate support -- use soft pillow under his head -- at least 4 - 6 hours per day . . . Note for areas of pressure especially bony prominences." R 4 was observed 3-23-92, in the morning, after bath in tub room, for dressing changes. Surveyor noted Stage II area on back of head, and the skin around excoriation was red. Certified Nursing Assistant stated R4 "should have padding on headrest." Headrest was noted to have bump toward lower end, which put pressure on the back of R4's head. **There was no padding on the wheelchair or documentation of the person's recurrent pressure sore.** Redness and bloody scab was noted on right ear, and **there was also no documentation or prevention of this.** Drainage was noted on the pillow, later on 3-23-92, from the right ear, when R4 turned off right side. There was a scab and dry area on left elbow noted while R4 was up in wheelchair, and **again there was no prevention or documentation of skin care.** On 3-23-92, during surveyor's observation of dressing of right chest wound from surgical chest tube removal, R4 was noted to have greenish/ yellowish drainage. No culture or sensitivity was done and R4's transfer sheet states, "Slight serous drainage from chest tube sit" on 2-17-92. **No documentation exists of this change of drainage type.** R4's doctor was notified immediately thereafter, on 3-23

and a culture and sensitivity was done and Bactroban was ordered two times per day with dressing.

Safety and Sanitation

Date of survey	Observations/Findings
9-6-91	During an interview with E16, surveyor was told by this employee that hydrotherapy was given to R49, R33, R18, and R77 by E16 in August. At that time, E16 used a germicidal disinfectant, "Unicide 256," instead of Betadine solution in the hydrotherapy tub while the persons being treated were in the tub. Surveyor questioned E16 at 2 different times to determine that E16 understood the surveyor's questions. Both times, E16 replied that **Unicide 256 was used, not only to sanitize the tub, but also in the tub while the persons listed earlier were receiving hydrotherapy. Unicide 256 is a disinfectant sanitizer used to effectively sanitize floors, walls and fixtures. It is not meant to be used as a skin disinfectant. Precautionary statements on the container label read, "CAUTION. KEEP OUT OF REACH OF CHILDREN. Corrosive. Causes eye and skin damage. Do not get in eyes, on skin or clothing. Wear goggles and rubber gloves when handling."** During the tour of Hubbard tub room, surveyor observed a one gallon container of solution labelled Unicide in letters printed with black marker pen. The label reading body/skin soap was also on the container. Surveyor observed no other containers of solutions in the tub room. Upon interviews with E17, E17 revealed to surveyor that Betadine solution was used in tub with residents and to sanitize the tub until a few months ago. According to E17, at that time, Unicide was implemented in the tub sanitization process. E17 claimed Betadine was still used while residents were in the tub. No bottles of Betadine were observed in the tub room by surveyor, however. In addition, the directions posted on the wall for tub disinfection and resident use were for Betadine. When E17 was questioned further on the use of Unicide, E17 responded that the same directions were used for Unicide as for Betadine.
3-5-92	The facility was observed not to be in compliance with applicable state regulations pertaining to safety in terms of hazardous chemicals not being stored in locked cabinets or rooms. **Gallon containers of bleach, wax stripper and wax were observed stored on a shelf in the unlocked housekeeping closet on the 1rst floor and on the counter in the unlocked soiled utility room on the 2nd floor.** The utility room is on a resident room hall and the housekeeping closet is used to get to dining activity rooms used by persons living in the facility. Staff reported that persons from the geriatric wings do go through the double doors to access

the ICF/DD Under Age 22 portions of the building. Surveyor observed some older persons who live in the facility doing just that several times although these particular people were not observed to be confused or disoriented. R10 from the geriatric wings, who is diagnosed with Alzheimers disease and is a wanderer, was observed to wander up to the double doors, accessing the ICF/DD portion of the building, but did not proceed through the doors on survey. The housekeeping closet is approximately 40 feet beyond the double doors.

3-26-92

Hazardous compounds and agents are not always found in locked cabinets or rooms. On 3-24-92 on tour of first floor, 2:00 p.m., **Hibowl cleaner trigger sprayer with unidentified contents, Meltfree, Spray Buff 5 - 5 gallon containers of stripper were found in unlocked, unattended janitor's closet. Residents who can ambulate in wheelchairs present in halls.**

3-26-92

Tub/shower locations have moldy buildup on floor/wall juncture. Shower curtains are moldy and/or ripped hanging from rod.

3-26-92

Equipment is found in use in an unclean and unsanitary condition. Wheelchairs have encrusted debris and dried spills on foot pedals, wheels, seats, head rests, arm rests, trays. Foot rests have peeling rubber mats. Visible soil is found on bases of wooden adaptive equipment. Wood is rough on bases and on trays worn and splintery. Duct tape is used to repair numerous wedges, wheelchair cushions, wheelchair head rests, chair cushions. Mats have peeling finish ripped or torn at seams or on surface.

4-16-92

On 4-15-92, at approximately 11:42 a.m., **the mobile medication cart was observed unlocked and unattended.** The nurse who was distributing medications was not visible at all. The Nurse Surveyor prompted another nurse who was in the classrooms to lock medication cart.

4-16-92

The facility has and had roof leaks that were observed by stained ceiling tiles that were dry in some areas and wet in others. In addition, water was observed to be entering from above the window casement in Team 8 and 10 and in classroom E and F. The window casement has deteriorated because of the moisture . . . **the same violation was cited during the 10-31-91 survey.**

4-16-92

The surveyor observed that the plastic baby bottles used for the delivery of formula or supplement to persons living in the facility are not being cleaned. Along with the Director of Nursing, the surveyor

found at least 18 bottles that had brown stains and dried food residue in the bottles. According to the Food Service Supervisor, the bottles are cleaned by using a bottle brush and then run in the dish machine. Because of the design, the bottles must be manually washed, rinsed and sanitized. The bottles were found in a dish machine glass rack in the medication room. **This was cited during the 10-31-91 survey.**

4-16-92

The facility's disaster plan does not address special provisions for the evacuation of the persons with physical disabilities living there. All of these persons are dependent on staff for evacuation. These persons are not ambulatory, although four can walk with a walker and/or verbal prompts.